Addressing Racial and Ethnic Disparities in Live Donor Kidney Transplantation: Priorities for Research and Intervention

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Summary: One potential mechanism for reducing racial/ethnic disparities in the receipt of kidney transplants is to enhance minorities’ pursuit of living donor kidney transplantation (LDKT). Pursuit of LDKT is influenced by patients’ personal values, their extended social networks, the health care system, and the community at large. This review discusses research and interventions promoting LDKT, especially for minorities, including improving education for patients, donors, and providers, using LDKT kidneys more efficiently, and reducing surgical and financial barriers to transplant. Future directions to increase awareness of LDKT for more racial/ethnic minorities also are discussed including developing culturally tailored transplant education, clarifying transplant-eligibility practice guidelines, strengthening partnerships between community kidney providers and transplant centers, and conducting general media campaigns and community outreach.

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Kidney transplantation represents an optimal therapy for end-stage renal disease (ESRD), offering patients improved survival and quality of life at less cost than dialysis.1,2 However, racial/ethnic minorities with ESRD trail behind Caucasians in their receipt of deceased donor kidneys.3,4 Research on racial/ethnic disparities in access to kidney transplant has shown that, compared with Caucasians, minorities are less likely to be referred and present for transplant evaluation,3,4 take longer to complete transplant evaluation,5 are less likely to be placed on the waiting list,6 wait longer for kidney transplantation,7 ascend up the waiting list more slowly,7 are less likely to undergo transplantation, and often suffer worse outcomes postoperatively.3,8,9

One potential mechanism for reducing racial/ethnic disparities in the receipt of transplants is to enhance minorities’ pursuit of living donor kidney transplantation (LDKT). LDKT, in which a living family member, friend, or another altruistic person donates their kidney to a patient with ESRD, yields better graft survival, lower rates of acute rejection, and improved patient survival10 compared with deceased donor transplantation. Because LDKT does not require potential recipients to be placed on a waiting list, it also bypasses many documented
barriers to the receipt of deceased kidney transplants, including longer deceased donor transplant waiting times and higher rates of immunologic incompatibility. LDKT also can occur before ESRD patients require dialysis, a treatment option called preemptive live donor transplantation (PLDT) that is associated with superior clinical outcomes. However, as of 2008, only 30% of living donors are racial/ethnic minorities, only 30% of LDKTs go to non-Caucasians, and racial/ethnic minorities are significantly less likely to receive PLDTs than Caucasians. The use of a socioecological model as a theoretical framework allows for examination of the influences of patients’ personal values, core family, extended social network, the health care system at large, and their community or culture on LDKT decision making and behavior (Fig. 1). Table 1 outlines known barriers to LDKT for racial/ethnic minorities and promising interventions to overcome these barriers for each level of the socioecological model.

**SOCIOECOLOGICAL THEORY DESCRIBING LDKT DECISION MAKING**

At the core of the socioecological model are patient-level factors: how patients think, feel, and make decisions about their illness and LDKT. Patients not pursuing LDKT tend to lack knowledge about the benefits of living donation over remaining on dialysis, have concerns about involving and risking a living donor’s health, or fear their own surgical pain and the possibility of the transplanted kidney failing. The effect of these factors on pursuit of LDKT among racial/ethnic minorities likely is exacerbated by minorities’ lower socioeconomic status, greater levels of occupational insecurity, and more transient health care coverage compared with their Caucasian counterparts.

Support of LDKT at the patient level varies among racial/ethnic minorities of different cultural backgrounds. For instance, mistrust of health care providers is more common for African Americans than Caucasians, which may affect their trust in physician’s recommendations for LDKT and cause suspicion of LKDT. In contrast, Hispanics’ strong sense of familial duty may affect their willingness to volunteer to be LDKTs compared with other ethnic groups.

**FAMILY- AND SOCIAL NETWORK–LEVEL FACTORS**

At its core, LDKT involves the potential kidney patient and his or her living donor. In addition, family members and friends are involved in supporting these individuals through evaluation, surgery, and recovery. Studies have shown that many patients, especially non-Caucasians and patients without a college degree, feel very uncomfortable talking about LDKT. In the case of racial/ethnic minorities, discussion about LDKT also may need to occur with a larger pool of potential living donors because it may be difficult to find a clinically suitable donor without kidney disease risk factors. This is reinforced by research suggesting that precursors for ESRD may spread through social networks. Also, research has shown that African American women with larger social support networks are more likely to complete pretrans-
Table 1. Possible Interventions to Overcome LDKT Barriers for Racial Minorities

<table>
<thead>
<tr>
<th>Barriers to Receipt of a LDKT, Particularly for Racial Minorities</th>
<th>Interventions That Have or Might Overcome These Barriers</th>
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<tbody>
<tr>
<td><strong>Patient/family level</strong></td>
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<td>Patient factors</td>
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<td>Variation in mortality/morbidity on dialysis or clinical</td>
<td>Improved LDKT education in transplant and dialysis</td>
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<td>suitability for transplant</td>
<td>centers</td>
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<td>Differing preferences for transplant</td>
<td>Improved preemptive living donor education</td>
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<td>Greater fears of transplant surgery or involving a LDKT</td>
<td>through community organizations</td>
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<td>Poorer LDKT knowledge</td>
<td>Interventions to improve patient’s health literacy</td>
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<td>Variation in willingness to ask others to be living donors</td>
<td>Interventions to reduce medical mistrust</td>
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<td>Variation in religious views or spirituality about health,</td>
<td>Community support groups for renal patients in early</td>
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<td>organ donation, and transplant</td>
<td>chronic kidney disease stages</td>
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<td>Mistrust of the medical establishment</td>
<td>Education addressing how to ask others to be living</td>
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<td>Practical barriers to transplant: no transportation or ability</td>
<td>donors</td>
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<td>to take off work for evaluation and recovery</td>
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<td>Transient health care coverage or lack of private insurance</td>
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<td>Not native English speakers or US citizens</td>
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<td>Improved LDKT education in transplant and dialysis centers</td>
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<td>Improved preemptive living donor education through community</td>
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<td>Education addressing how to ask others to be living donors</td>
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<td>Increased availability of paired donation and non-directed</td>
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<td>donation programs</td>
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<td>Improved LDKT education reaching potential living donors on</td>
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<td>the web</td>
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<td>Financial assistance covering LDKT-related expenses</td>
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<td>Transplant education involving the family and prospective</td>
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<td>donors in multiple languages</td>
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<td>Media campaigns to educate community about LDKT</td>
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<td>Lack of eligible living donors because of higher rates of</td>
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<td>diabetes, hypertension, and kidney disease in families of</td>
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<td>racial minorities</td>
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<td>Lack of awareness someone could be a LDKT</td>
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<td>Higher fears about being a LDKT</td>
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<td>Practical barriers: no transportation or ability to take off</td>
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<td>Cultural differences in family decision making,</td>
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<td>communication, and support for LDKT</td>
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<td>System level</td>
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<td><strong>Health care organization factors</strong></td>
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<td>Insufficient time for potential donor and recipient education</td>
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<td>about LDKT</td>
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<td>Complex and inefficient transplant evaluation</td>
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<td>Lack of LDKT educational resources in multiple languages</td>
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<td>and for low health literacy patients</td>
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<td>Healthy potential living donors do not match their recipients</td>
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<td>System level</td>
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<tr>
<td><strong>Community and societal level</strong></td>
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<td>Lack of health insurance results in delayed access to CKD</td>
<td>Universal access to health care</td>
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<td>care—minorities present to emergency rooms in ESRD</td>
<td>Provide incentives for appropriate referrals (ie, pay</td>
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<td>Providers receive more reimbursement for dialysis care than</td>
<td>for performance)</td>
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<td>transplant referral</td>
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<td>Costs of immunosuppressant drugs after 3 years stop minorities from pursuing LDKT</td>
<td>Proposals to extend Medicare immunosuppressant drug coverage for the life of the transplant</td>
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plant evaluation than African American women with less support.\textsuperscript{31}

**HEALTH CARE SYSTEM–LEVEL FACTORS**

Patients interested in LDKT also encounter barriers at every stage of the clinical pathway, including being aware of their medical eligibility, completing transplant evaluation, finding a matching living donor, completing donor and recipient evaluations, and receiving transplants. System-level barriers for racial/ethnic minorities include disproportionate access to the option of LDKT, poor LDKT education, and inefficient clinical evaluations and care. Possibly because of variation in their training or subconscious patient stereotyping, health care providers may overemphasize racial/ethnic minority patients’ reluctance to receive transplants or hold biases that racial/ethnic minorities do better on dialysis than nonminorities.\textsuperscript{8,32,33} Their rates of transplant referral may vary because of beliefs that minorities or individuals of low socioeconomic status may be more likely to drop out of evaluation or have less successful transplants.\textsuperscript{34,35} Also, some providers have insufficient time to educate patients about LDKT or work in environments with inadequate educational resources.\textsuperscript{4,36} One study found that 78\% of surveyed dialysis patients reported no or incomplete knowledge about LDKT.\textsuperscript{37} Cultural or language barriers also may limit providers from being able to truly understand patients’ LDKT preferences.\textsuperscript{38}

**COMMUNITY- AND SOCIETY-LEVEL FACTORS**

Community- and society-level factors affecting transplant decision making include availability of health insurance, government regulations regarding transplantation and organ donation, and cultural values and customs. Persons of low socioeconomic status and without private insurance are less likely to be listed for transplant and less likely to undergo PLDT.\textsuperscript{39} Research has shown that more than 80\% of the general public is supportive of financial incentives such as reimbursement for medical costs and paid leave for LDKT, with African Americans reporting more support for financial incentives than Caucasians.\textsuperscript{40} Over the past 10 years, state and national legislation has been enacted to reduce the financial burden of LDKT through tax incentives, the provision of paid and unpaid leave, and the reimbursement of direct costs. However, such legislation is not yet associated with any increase in LDKT rates.\textsuperscript{41}

**INTERVENTIONS ADDRESSING BARRIERS TO LDKT**

To provide insight for stakeholders seeking to address and overcome racial/ethnic disparities in LDKT, we discuss known LDKT interventions at every level of the socioecological model. This review discusses research and interventions promoting LDKT, especially for minorities, including improving education for patients, donors, and providers, using LDKT kidneys more efficiently, and reducing surgical and financial barriers to transplant.

**PATIENT-LEVEL INTERVENTIONS**

**Improved Dialysis Education About LDKT**

Minority and low-income populations are less knowledgeable and receive less education about transplants than other groups.\textsuperscript{42} At least two group randomized controlled trials have studied whether improved dialysis center LDKT education increases pursuit of transplant and LDKT. Transplant-eligible patients in these studies watched videos sharing recipient and living donor stories, received educational brochures, and had LDKT conversations. In one study, compared with their baseline attitudes, African Americans, younger patients, and patients who spent less time on dialysis were shown to be significantly more willing to pursue LDKT after receiving education compared with patients in control dialysis centers.\textsuperscript{43} In a second study, patients in dialysis centers receiving LDKT education were significantly more likely to share education with their support network, make a list of potential living donors, and discuss LDKT with others compared with patients in control dialysis centers. Also, in a subgroup analysis, African American patients receiving LDKT education were significantly more likely than their
Caucasian counterparts to make a list of potential donors and to discuss LDKT with others. Improved Education about Preemptive Transplantation

Although educating patients about PLDT also could enable more patients to bypass dialysis entirely, it is difficult to locate eligible patients before they reach ESRD. Minority patients generally access health care services less than non-minorities and are more likely to present to nephrologists or the emergency room in full kidney failure. Although currently there is a paucity of data about promoting PLDT, two randomized controlled trials partnering with community nephrologists and patient advocacy organizations are being conducted to assess the effectiveness of patient educational initiatives on increasing rates of PLDT for minorities. Methods for improving PLDT awareness outside of the clinical setting also should be explored further.

FAMILY AND SOCIAL NETWORK INTERVENTIONS

Home-Based Education for Patients and Families

Patients pursuing LDKT want detailed information about the evaluation, surgery, and medical tests required for recipients and donors. Several transplant centers have increased LDKT rates by offering formal family education programs and targeting African Americans. However, traditional clinic education about LDKT often is brief, presented early in the patients’ decision-making process, and only to those who attend medical appointments. Rodrigue et al conducted a randomized controlled trial of an educational program in which health professionals discussed LDKT with prospective recipients and their support network either in the clinic or their homes. Compared with traditional clinic-based education, significantly more patients in the home-based condition, particularly African Americans, had living donor inquiries, evaluations, and LDKTs. This program allowed more patients and their support networks to learn about LDKT without taking time off from work to go to the transplant center and enabled interested potential living donors to volunteer without requiring kidney recipients to ask directly.

HEALTH CARE SYSTEM–LEVEL INTERVENTIONS

Improving Dialysis Provider Education About LDKT

The Medicare Improvements for Patients and Providers Act of 2008 mandates that patients with advanced kidney dysfunction receive education about all ESRD treatment options, tailored to the specific needs of individual patients and populations. However, dialysis providers may not have received enough education about LDKT themselves to accomplish this task. One study of dialysis providers representing 254 centers in four states revealed that only 41% felt knowledgeable enough to answer patients’ transplant questions, with only 29% of these centers having a formal transplant education program. An ongoing trial educating dialysis providers on how to discuss LDKT with their patients is occurring in partnership with the Centers for Medicare and Medicaid Services Network 12. The goal of this intervention is to standardize provider knowledge about transplants and to increase the availability of patient education for all transplant-eligible dialysis patients. As one of its main outcomes, this study will assess the effect of provider education on reducing racial/ethnic disparities in the receipt of LDKT.

Paired Donation and Nondirected Donation Programs

One third of willing living donors are ruled out because of blood type or antibody incompatibility with their intended recipients. Paired donation programs (where an incompatible donor donates to another recipient so that his/her intended recipient can receive a kidney from another living donor or the deceased donor pool), and nondirected donation programs (where charitable individuals anonymously donate living donor kidneys to patients on the waiting list) have been developed to efficiently use available living donors without matching recipients. To date, 398 paired donations, 207
list paired donations, and more than 500 non-directed donations have occurred.17

In 2008, a national Kidney Paired Donation pilot program was approved by the United Network for Organ Sharing to increase living donor access to this option nationally. Although these programs allow more recipients to receive the health benefits of living donor kidneys,55-57 concerning trends are being reported in which Caucasians and patients of higher socioeconomic status are more likely to participate than other racial groups, possibly creating, rather than reducing, LDKT disparities.58

Systematizing Living Donor Care in Transplant Centers

Interventions to standardize education and simplify care for living donors also may help to increase LDKT rates. To reduce confusion, the Living Donor Consensus Group has developed a set of recommendations standardizing what information should be communicated to living donors at transplant centers.59,60 Growing use of laparoscopic and mininephrectomy surgical techniques, which reduce donors’ incisions and shorten recovery times, has been shown to increase LDKT rates.61-63

COMMUNITY AND SOCIETY LDKT INTERVENTIONS

Reimbursement of Living Donation Expenses for Eligible Donors

In 2007, the National Living Donor Assistance Center (NLDAC) was established to assist individuals with out-of-pocket expenses associated with living donation. For potential living donors who meet specific financial eligibility criteria, the NLDAC provides up to $6,000 in reimbursement for the costs of donor evaluation, surgery, and follow-up evaluation, including hotel, travel, and meal expenses. Currently, more than 100 transplant centers have filed NLDAC applications, with more than 200 potential living donors receiving funds (NLDAC communication, Katrina Crist, October 1, 2008). With 40% of applicants reporting that they would be unable to afford to donate without NLDAC financial support, this is an important initiative for overcoming financial disincentives to living donation. The effect of the NLDAC program on LDKT rates for racial/ethnic minorities has not yet been assessed.

FUTURE DIRECTIONS TO OVERCOME RACIAL/ETHNIC DISPARITIES IN LDKT

In addition to the intervention approaches discussed, there are many other strategies for reducing racial/ethnic disparities in LDKT that need additional study. Hispanics (41%), African Americans (25%), and Asian/Pacific Islanders (13%) have suboptimal levels of health literacy compared with Caucasians (9%). Therefore, culturally tailored transplant education approaches must be made available at appropriate reading/literacy levels and in other languages, with the use of live interpreters when appropriate.64,65 Since many potential living donors first learn about LDKT online,66 information must be made easily available through common search engines. Finally, an exploration of the effectiveness of different strategies for involving patients’ families and social networks in learning about LDKT and locating potential living donors still is needed.

Interventions aimed at the health care system or provider levels, where patients most often receive information, ultimately may reach more racial/ethnic minorities. Strengthening partnerships between community nephrologists and transplant centers may enable more transplant-eligible patients to be identified, educated, and referred. Broad dissemination of clinical practice guidelines outlining which patients are transplant-eligible and when referral for PLDT should occur may help resolve provider uncertainty. Since greater continuity of care is associated with higher levels of patient trust,67 interventions that establish strong and consistent physician-patient relationships also may contribute to higher LDKT rates for minorities.

At the community level, media campaigns and community outreach targeting racial/ethnic minorities may enhance awareness of the need for LDKT.68 Interventions encouraging donor registration through the Registry of Motor Vehicles may have important spill-over effects for LDKT, especially by increasing discussion about the possibility of organ donation within families.
In closing, multiple forums on reducing racial/ethnic disparities recommend linking system improvements to reducing racial disparities, incentivizing reduction of disparities, establishing a diverse health care workforce and culturally competent providers, and expanding access to health services and insurance coverage. It is likely that these approaches would impact LDKT rates for racial/ethnic minorities. However, there is also a significant lack of information about how LDKT decisions are made, especially for racial/ethnic minorities. Research that enhances knowledge about the key determinants of decision making for minority recipients and potential donors and that addresses system- and community-level LDKT barriers still is needed to understand the optimal mechanisms through which LDKT disparities can be ameliorated.

REFERENCES


