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

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Abstract

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 healthcare 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, utilizing LDKT kidneys more efficiently, and reducing surgical and financial barriers to transplant. Future directions to increase awareness of LDKT for more racial/ethnic minorities are also 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.

Keywords

Live Donor Kidney Transplantation; LDKT; disparities in kidney transplantation; kidney transplant barriers

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 kidney transplants.^{1, 2} Research on racial/ethnic disparities in access to kidney transplant has shown

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that, compared to non-minorities, 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 post-operatively.^{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, where 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. Since 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,^{3, 11} including longer deceased donor transplant waiting times and higher rates of immunological incompatibility.¹² LDKT can also occur before ESRD patients require dialysis, a treatment option called preemptive live donor transplantation (PLDT) that is associated with superior clinical outcomes.^{13–15} However, as of 2008, only 30% of living donors are racial/ethnic minorities, only 30% of LDKTs go to non-Caucasian recipients (www.unos.org), and racial/ethnic minorities are significantly less likely to receive PLDTs than Caucasians.¹⁶

Social-Ecological Theory Describing LDKT Decision-Making

Utilizing a socio-ecological model as a theoretical framework allows for examination of the influences of patients' personal values, core family, extended social network, the healthcare system at large, and their community or culture on LDKT decision-making and behavior (Figure 1). Table 1 outlines known barriers to LDKT for racial/ethnic minorities and promising interventions to overcome these barriers for each level of the socio-ecological model.

Patient Level Factors

At the core of the social-ecological 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,¹⁷ 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.^{18, 19} The effect of these factors on pursuit of LDKT among racial/ethnic minorities is likely exacerbated by minorities' lower socioeconomic status, greater levels of occupational insecurity, and more transient healthcare coverage compared to their Caucasian counterparts.^{20, 21}

Support of LDKT at the patient level varies among racial/ethnic minorities of different cultural backgrounds. For instance, mistrust of healthcare providers is more common for African-Americans than Caucasians,²² which may affect their trust in physician's recommendations for LDKT and cause suspicion of LDKT.^{22–24} In contrast, Hispanics' strong sense of familial duty²⁵ may affect their willingness to volunteer to be LDKTs compared with other ethnic groups.²⁶

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.^{18, 27, 28} In the case of racial/ethnic minorities, discussion about LDKT also may need to occur with a larger pool of potential living donors, since 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.²⁹ Also, research has shown that African-American women with larger social support networks are more likely to complete pre-transplant evaluation than African-American women with less support.³⁰

Healthcare 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 due to 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 non-minorities.^{8, 31, 32} 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.^{33, 34} Also, some providers have insufficient time to educate patients about LDKT or work in environments with inadequate educational resources.^{4, 35} One study found that 78% of surveyed dialysis patients reported no or incomplete knowledge about LDKT.³⁶ Cultural or language barriers may also limit providers from being able to truly understand patients' LDKT preferences.³⁷

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 preemptive living donor transplantation, (PLDT).³⁸ Research has shown that over 80% of the general public is supportive of financial incentives like reimbursement for medical costs and paid leave for LDKT, with African-Americans reporting more support for financial incentives than Caucasians.³⁹ 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.⁴⁰

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 socio-ecological model. This review discusses research and interventions promoting LDKT, especially for minorities, including improving education for patients, donors, and providers, utilizing 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 transplant than other groups.⁴¹ 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 to 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 to patients

in control dialysis centers.⁴² 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 to 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.⁴³

Improved Education about Preemptive Transplantation—Although educating patients about PLDT also could enable more patients to bypass dialysis entirely,⁴⁴ 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.^{45, 46} 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.⁴⁷ Several transplant centers have increased LDKT rates by offering formal family education programs and targeting African-Americans.⁴⁸ However, traditional clinic education about LDKT is often brief, presented early in patients' decision-making process, and only to those who attend medical appointments. Rodrigue and colleagues conducted a randomized controlled trial of an educational program where 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.^{49, 50} This program allowed more patients and their support networks to learn about LDKT without taking time off work to go to the transplant center and enabled interested potential living donors to volunteer without requiring kidney recipients to ask directly.

Healthcare 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.⁵¹ 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 (CMS) Network 12. The goal of this intervention is to standardize provider knowledge about transplant and 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 Non-Directed Donation Programs—One-third of willing living donors are ruled out due to blood type or antibody incompatibility with their intended recipients.⁵² 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 non-directed donation programs (where charitable individuals anonymously donate living donor kidneys to patients on the waiting list) have been developed to efficiently utilize available living donors without matching recipients.⁵³ To date, 398 paired donations, 207 list paired donations, and over 500 non-directed donations have occurred (www.unos.org).

In 2008, a national Kidney Paired Donation pilot program was approved by the United Network for Organ Sharing (UNOS) to increase living donor access to this option nationally. Although these programs allow more recipients to receive the health benefits of living donor kidneys, ^{54–56} concerning trends are being reported where Caucasians and patients of higher socioeconomic status are more likely to participate than other racial groups, possibly creating rather than reducing LDKT disparities. ⁵⁷

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.^{58, 59} Growing use of laparoscopic and mini-nephrectomy surgical techniques, which reduce donors' incisions and shorten recovery times, has been shown to increase LDKT rates.^{60, 61, 62}

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 \$6000 in reimbursement for the costs of donor evaluation, surgery, and follow-up, including hotel, travel and meal expenses. Currently, over 100 transplant centers have filed NLDAC applications, with over 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.^{63, 64} Since many potential living donors first learn about LDKT online,⁶⁵ 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 is still needed.

Interventions aimed at the health care system or provider levels, where patients most often receive information, may ultimately 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,⁶⁶ interventions that establish strong and consistent physician-patient relationships may also 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.⁶⁷ 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 healthcare workforce and culturally competent providers, and expanding access to health services and insurance coverage.^{68–70} 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 is still needed to understand the optimal mechanisms through which LDKT disparities can be ameliorated.

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Adapted from Bronfenbrenner's Ecological Systems Theory, 1998

Figure 1.
Social-Ecological Transplant Model

Table 1**Possible Interventions to Overcome LDKT Barriers for Racial Minorities**

	Barriers to Receipt of a LDKT, Particularly for Racial Minorities	Interventions that have or might overcome these barriers
PATIENT/FAMILY LEVEL		
Patient Factors	<ul style="list-style-type: none"> • Variation in mortality/morbidity on dialysis or clinical suitability for transplant • Differing preferences for transplant • Greater fears of transplant surgery or involving a LDKT • Poorer LDKT knowledge • Variation in willingness to ask others to be living donors • Variation in religious views or spirituality about health, organ donation, & transplant • Mistrust of the medical establishment • Practical barriers to transplant: no transportation or ability to take off work for evaluation and recovery • Transient healthcare coverage or lack of private insurance • Not native English speakers or US citizens 	<ul style="list-style-type: none"> • Improved LDKT education in transplant & dialysis centers • Improved preemptive living donor education through community organizations • Interventions to improve patient's health literacy • Interventions to reduce medical mistrust • Community support groups for renal patients in early CKD stages • Education addressing how to ask others to be living donors
Family and Social Network Factors	<ul style="list-style-type: none"> • Lack of eligible living donors due to higher rates of diabetes, hypertension, and kidney disease in families of racial minorities • Lack of awareness could be a LDKT • Higher fears about being a LDKT • Mistrust of the medical establishment • Practical barriers: no transportation or ability to take off work for LDKT evaluation and recovery • Transient healthcare coverage or lack of private insurance • Not native English speakers or US citizens • Cultural differences in family decision-making, communication, and support for LDKT 	<ul style="list-style-type: none"> • Increased availability of Paired Donation and Non-Directed Donation programs • Improved LDKT education reaching potential living donors on the web • Financial assistance covering LDKT-related expenses • Transplant education involving the family & prospective donors in multiple languages • Media campaigns to educate community about LDKT
PROVIDER FACTORS		
Physician and/or Healthcare Provider Factors	<ul style="list-style-type: none"> • Lack of physicians and healthcare providers who are racial minorities • Physician beliefs about racial differences in morbidity and mortality with transplant versus dialysis 	<ul style="list-style-type: none"> • Establish a diverse & culturally competent healthcare workforce • Establish practice guidelines for transplant eligibility & referral

	Barriers to Receipt of a LDKT, Particularly for Racial Minorities	Interventions that have or might overcome these barriers
	<ul style="list-style-type: none"> • Perceptions of patients' suitability for transplant – unconscious stereotyping • Insufficient training in transplant (for dialysis providers) 	<ul style="list-style-type: none"> • Train dialysis providers how to educate patients about LDKT
Physician-Patient Factors	<ul style="list-style-type: none"> • Patient confusion about LDKT due to inconsistent transplant education and referral across multiple providers • Less established or quality patient-physician relationship • Poor patient-physician communication regarding LDKT • Cultural or language barriers between patients and physicians 	<ul style="list-style-type: none"> • Develop culturally competent education at appropriate literacy levels in multiple languages • Increase the availability of interpreters • Strengthen communication between transplant, dialysis, and community physicians
SYSTEM LEVEL		
Healthcare Organization Factors	<ul style="list-style-type: none"> • Insufficient time for potential donor and recipient education about LKDT • Complex & inefficient transplant evaluation • Lack of LDKT educational resources in multiple languages and for low health literacy patients • Healthy potential living donors do not match their recipients 	<ul style="list-style-type: none"> • Streamline transplant and living donor evaluation and surgery • Chronic Care Model or Guided Care approach to help ensure patients complete transplant evaluation • Establish standard LDKT educational programs using web, video and print materials • Establish National Paired Donation program
Community and Societal Level	<ul style="list-style-type: none"> • Lack of health insurance results in delayed access to CKD care - minorities present to emergency rooms in ESRD • Providers receive more reimbursement for dialysis care than transplant referral • Costs of immunosuppressant drugs after three years stop minorities from pursuing LDKT 	<ul style="list-style-type: none"> • Universal access to healthcare • Provide incentives for appropriate referrals (i.e., Pay for Performance) • Proposals to extend Medicare immunosuppressant drug coverage for the life of the transplant