

Living Donor Kidney Transplantation: Overcoming Disparities in Live Kidney Donation in the US—Recommendations from a Consensus Conference

James R. Rodrigue,* Abby Swanson Kazley,[†] Didier A. Mandelbrot,[‡] Rebecca Hays,[‡] Dianne LaPointe Rudow,[§] and Prabhakar Baliga[†]

Abstract

Despite its superior outcomes relative to chronic dialysis and deceased donor kidney transplantation, live donor kidney transplantation (LDKT) is less likely to occur in minorities, older adults, and poor patients than in those who are white, younger, and have higher household income. In addition, there is considerable geographic variability in LDKT rates. Concomitantly, in recent years, the rate of living kidney donation (LKD) has stopped increasing and is declining, after decades of consistent growth. Particularly noteworthy is the decline in LKD among black, younger, male, and lower-income adults. The Live Donor Community of Practice within the American Society of Transplantation, with financial support from 10 other organizations, held a Consensus Conference on Best Practices in Live Kidney Donation in June 2014. The purpose of this meeting was to identify LKD best practices and knowledge gaps that might influence LDKT, with a focus on patient and donor education, evaluation efficiencies, disparities, and systemic barriers to LKD. In this article, we discuss trends in LDKT/LKD and emerging novel strategies for attenuating disparities, and we offer specific recommendations for future clinical practice, education, research, and policy from the Consensus Conference Workgroup focused on disparities.

Clin J Am Soc Nephrol 10: 1687–1695, 2015. doi: 10.2215/CJN.00700115

Introduction

Live donor kidney transplantation (LDKT) has superior outcomes relative to chronic dialysis and deceased donor kidney transplantation for patients with kidney failure (1–3). Unfortunately, LDKT is less likely to occur in minorities, older adults, and poor patients than in those who are white, younger, and have higher household income (1,4–6). Preemptive (*i.e.*, before dialysis initiation) LDKT also is less likely in patients with these characteristics (1). Such differences likely represent disparities, defined as differences that are unnecessary, avoidable, and modifiable (4). Improving LDKT access in patients with historically low rates of the most optimal form of treatment is an obligation shared by transplant professionals, community nephrologists, and primary care physicians. In particular, community nephrologists and primary care physicians, who collectively care for nearly all patients with CKD, are best positioned to provide early patient education about transplant options, review the survival advantages of LDKT, and provide impartial and trusted answers to questions from patients and family members about possible living kidney donation (LKD) (7,8).

The shifting LKD landscape is embedded within LDKT disparities (9). LDKT is made possible only by healthy and willing adults who meet eligibility criteria to serve as living donors. LKD rates appear to be declining in men, siblings, blacks, and younger and low-income adults (9). Changes in the characteristics of living donors may have LDKT implications for some

transplant candidates more than others. Understanding disparities and differences in both LDKT and LKD, respectively, is important for identifying educational, clinical, and policy strategies that may help to improve access to LDKT for all patients.

The Live Donor Community of Practice within the American Society of Transplantation, with the financial support of 10 other organizations, held a Consensus Conference on Best Practices in Live Kidney Donation in June 2014 (10). The purpose of this meeting was to identify LKD best practices and knowledge gaps that might influence LDKT, with a focus on patient and donor education, evaluation efficiencies, disparities, and systemic barriers to LKD. Conference participants did not address practices specific to kidney paired donation (KPD) or follow-up care practices because these topics were extensively reviewed at other recent meetings (11,12). In this article, we discuss trends in LDKT/LKD and emerging novel strategies for attenuating disparities, and we offer specific recommendations for future clinical practice, education, research, and policy from the Consensus Conference Workgroup focused on disparities.

Notable Trends in LDKT/LKD

Workgroup members considered several historical and emerging trends in LDKT and LKD, with consideration for how such trends may further exacerbate LDKT disparities if no action is taken by key stakeholders. Although we recognize that there are other

*Transplant Institute, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, Massachusetts; [†]Department of Surgery, Medical University of South Carolina, Charleston, South Carolina; [‡]Transplant Center, University of Wisconsin Hospital and Clinics, Madison, Wisconsin; and [§]Recanati Miller Transplantation Institute, Mount Sinai Medical Center, New York, New York

Correspondence: Dr. Prabhakar Baliga, Division of Transplantation, Department of Surgery, Medical University of South Carolina, P.O. Box 250613, Charleston, SC 29425. Email: baligap@muscc.edu

noteworthy trends in LKD (*e.g.*, substantial increase in unrelated living donors), we focused our review of the literature and workgroup discussions on LDKT and LKD trends related to race and ethnicity, income, age, sex, and geography. This article is not intended to be a comprehensive summary of LDKT disparities and LKD differences, because others have provided exceptional reviews of this literature (4,9,13–15). Rather, our intention here is to provide a sufficient backdrop to frame the workgroup’s discussions and recommendations.

Race/Ethnicity

Different patterns of racial and ethnic disparities in kidney transplantation suggest that some minorities, relative to non-Hispanic white patients, may experience more kidney transplant access barriers, be more likely to have initiated dialysis at the time of transplant referral, wait longer for a deceased donor transplant, have higher mortality rates on the waiting list, and have less optimal transplant outcomes (4,6,13–19). Because the proportion of patients on the kidney transplant waiting list is increasing for racial/ethnic minorities (while declining for non-Hispanic whites) (1), the extreme shortage of deceased donor kidneys is likely to exacerbate these transplant disparities in the years ahead. These factors escalate the relative importance of LDKT access for racial/ethnic minority patients. As a percentage of total kidney transplants within the race/ethnicity category, minorities were far less likely than whites to receive a LDKT over the last decade (2004–2013), as highlighted in Figure 1 (1). This trend is further exemplified by a decline in LKD, particularly among blacks, in which LKD has declined by about 30% over the last decade (1,9). One notable caveat, however, is that as a percentage of LDKTs, blacks in 2014 were more likely than other minorities and non-Hispanic whites to receive LDKT *via* KPD (1). There are racial/ethnic variations in long-term adverse health outcomes after donation. For instance, after LKD, blacks have higher risks of ESRD and hypertension and Hispanics have higher risks of

hypertension compared with non-Hispanic whites (20,21). Although the discovery of a genetic marker (*i.e.*, APOL1) to predict risk of future kidney disease in blacks may hold some promise in attenuating this disparity in living donor outcome, it has not yet been integrated into the clinical evaluation of potential living donors (22–24). As noted by Tan *et al.* (25) in this issue of *CJASN*, the lack of consensus about how best to screen potential living donors in these racial/ethnic groups may be contributing to variable eligibility criteria at transplant programs and heightened uncertainty by potential donors.

There are several potential barriers to LDKT for racial/ethnic minorities. These barriers are multisystemic and multilayered, because they include those pertaining to healthcare systems and access to care, transplant center process and care delivery, the transplant candidate and his or her support system, and ways that cultural values and religious beliefs influence concepts about health and approach to healthcare. To date, the effect of race/ethnicity on LDKT access has not been adequately described by the kidney transplant community, particularly in capturing differences in barriers within widely diverse racial/ethnic groups or in identifying differences in point-of-access problems. However, broadly described and starting with influence of cultural identity, some minorities with kidney failure may cope with the need for transplantation and the possibility of LDKT differently than non-Hispanic whites, and they may be more likely to deny the need for kidney transplantation, have religious objections to transplantation, question the survival and quality of life benefits of transplantation, and mistrust the healthcare system because of their experience of discrimination in accessing healthcare in the past (14,26–30). Even for blacks and Hispanics who have decided to pursue transplantation and are on the waiting list, many have not actively considered the LDKT option and some harbor distrust and equity concerns affecting willingness to participate in KPD (29,31,32). These findings indicate that LDKT educational processes, particular those from initial diagnosis of CKD to referral for transplantation,

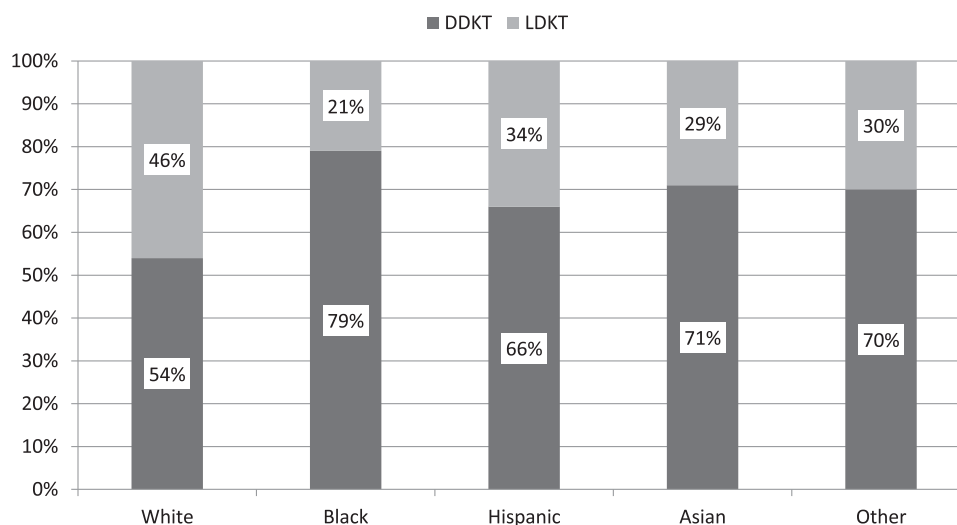


Figure 1. | Live donor versus deceased donor kidney transplantation as a percentage of total transplants, within race/ethnicity (United States, 2004–2013). DDKT, deceased donor kidney transplantation; LDKT, live donor kidney transplantation.

are in need of modification to effectively bridge barriers and provide a more navigable path.

In the patients' support system (*i.e.*, potential living donors), healthy family members and friends may lack awareness of the LDKT benefits or risks of LKD, may have inaccurate assumptions about their suitability for living donation, and may have high mistrust of the health-care system (13,33). In addition, the same religious beliefs that contribute to lower rates of deceased donation may also be present in circumstances in which living donation is being considered (*e.g.*, bodily integrity, potential interference with future resurrection, etc.) (34–36). Even if there are willing living donors, certain minorities are more likely than non-Hispanic whites to have medical conditions (*e.g.*, diabetes, hypertension, obesity) that disqualify them as donors and are more likely to be lost to follow-up once the donor evaluation is initiated (26,37,38).

Income

Lower household income is associated with more limited access to kidney transplantation, higher death rates on the waiting list, and lower rates of LDKT (6,39). Preemptive LDKT has the strongest correlation with patient higher-income status. Given that patients qualify for renal Medicare only after initiating RRT, the poor (who are much less likely to have private insurance) have extremely limited access to transplant evaluation (or LKD workup) before entering ESRD. In addition, it is known that, by and large, living donor-recipient pairs come from the same socioeconomic status group (40). Although this is an understudied area, pairs with limited financial resources may be less likely to pursue LDKT or LKD because of the perceived burden of lost wages, difficulty accessing required health maintenance screenings, and other direct or indirect costs for the living donor. Patients with more financial resources can legally offset some of these living donation costs by reimbursing the donor, but this is not possible for those with limited income.

The LDKT and LKD financial concerns of patients and potential donors are not unfounded (41–43). The workgroup noted the likelihood that the financial effect of LKD is a

significant driver of disparities in LDKT, both for those in lower socioeconomic classes and for many members of minority groups. Although this topic was explored in more depth in another workgroup (44), the finances of access to care and burdens of LKD were central to our workgroup's discussion. Unfortunately, living donor costs have not been systematically captured by the transplant community, although some have estimated total costs to range from \$0 to \$20,000, with an average of approximately \$5000 (41–43,45). Concern about these costs deters both transplant candidates from talking to others about possible donation and potential living donors from pursuing donation (46). Precisely how many potential donors choose not to donate because of anticipated financial hardship is currently unknown and warrants investigation, but it is not unreasonable to suggest that these concerns may have contributed to the recent LKD decline during the economic recession in the United States. Indeed, Gill *et al.* (47,48) found that LKD increased the most among those in higher-income groups from 1999 to 2004; however, since 2004, LKD has declined the most in low-income groups, thus accelerating the income difference in LKD rates. In addition, the LKD decline has been most dramatic in low-income blacks relative to all other racial/ethnic and income groups (47).

Age

In the last decade, the number of adults added to the kidney transplant waiting list has increased by about 4% annually (1). However, much of this increase is attributable to the addition of older adults to the waiting list. Although the number of adults aged 18–49 years who are added to the waiting list has remained very stable in the past decade, there has been a persistent annual increase of new waiting list additions for adults aged 50–64 years and ≥65 years (mean annual increases of 4.2% and 7.2%, respectively). As illustrated in Figure 2, relative to younger adults, older transplant candidates are less likely to receive a LDKT (1). There are several possible explanations for lower LDKT rates in older adults. As patients age, so do their social networks. As the patient's siblings, friends, and coworkers age, they are less likely to meet LKD eligibility criteria (49). Our workgroup noted anecdotally that some

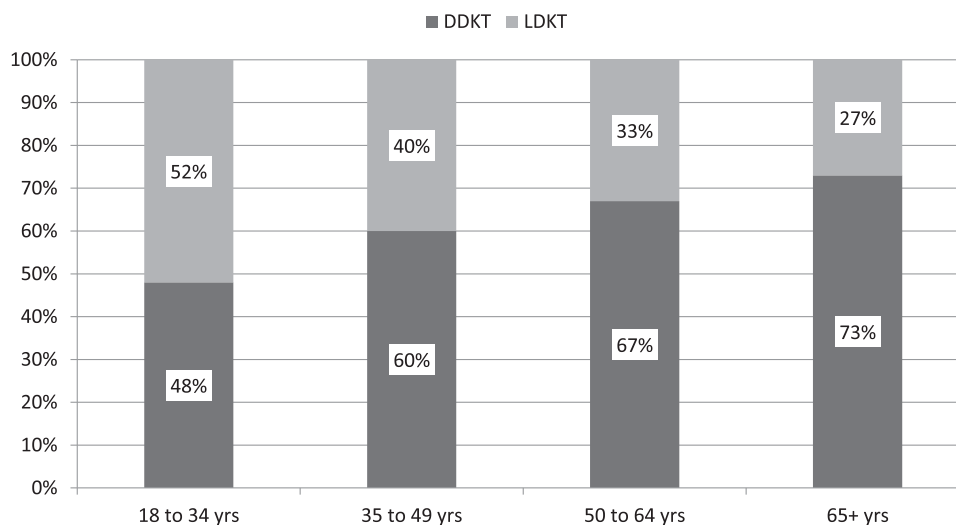


Figure 2. Live donor versus deceased donor kidney transplantation as a percentage of total transplants, within age category (United States, 2004–2013). DDKT, deceased donor kidney transplantation; LDKT, live donor kidney transplantation.

patients and transplant programs are less willing to accept kidneys from much younger living donors (*e.g.*, adult grandchildren) for transplantation into older adults with limited life expectancy. In addition, the Organ Procurement and Transplantation Network recently implemented a new national kidney allocation scheme for deceased donor transplantation. This new system may further exacerbate age disparity in LDKT, because its prioritization of maximizing organ utility is likely to decrease the ability of older transplant candidates to receive deceased donor kidneys with a lower donor risk profile (50). Importantly, past policy changes in deceased donor kidney allocation adversely affected LDKT rates. For instance, LDKT rates for pediatric patients declined substantially after implementation of a new policy prioritizing allocation of kidneys from younger deceased donors (aged <35 years) to pediatric recipients (aged <18 years) (9,51).

As one might expect, the increase in the number of older adults added to the kidney transplant waiting list is matched by a similar increase in the number of older living kidney donors in the last decade. Indeed, the overall decline in LKD has occurred primarily among individuals aged <50 years; from 2004 to 2013, LKD in this demographic has declined an average of 3% per year (1). By contrast, in this same time period, LKD has increased 2% per year for those aged ≥ 50 years. Importantly, older donors do not appear to be at any heightened risk of poor outcomes after donation (52), and LDKT outcomes from older living donors are comparable to receiving a kidney from a deceased standard criteria donor (53). Research is needed to examine the underlying mechanism for the shift in living donor age and whether it persists after implementation of the new kidney allocation system.

Sex

Relative to men, women experience more kidney transplant access barriers and wait longer for kidney transplantation (1), perhaps due to being more highly sensitized

because of pregnancy history and the associated difficulty in finding a donor match, and they are less likely to pursue LDKT (54). Gill *et al.* (55) recently found that overweight and obese women are significantly less likely to receive LDKT compared with overweight and obese men. Despite these notable barriers, there does not appear to be a sex disparity in LDKT because women comprise 40% of the candidates on the transplant waiting list and are recipients of 39% of all kidney transplants annually (1). Importantly, over the past decade, the percentage of LDKTs relative to total number of kidney transplants for women is very similar to that for men (a mean of 37% annually for both sexes). In addition, as a percentage of total LDKTs performed, women are more likely than men to receive LDKT *via* KPD (12% versus 8%) (1).

Women represent the majority of living donors in the United States, accounting for 60% of all living kidney donors in the past decade (1). This trend is likely to continue because the number of male living donors has declined in recent years (9). Living donors have historically been members of the transplant recipient's immediate family (although these demographics are changing). Given that 55%–60% of adults with ESRD are men (56), it makes sense that a higher number of sibling and spousal donors are women (57). Currently, 14% of LDKTs for men occur from spouse donation compared with only 8% of LDKTs for women (1). The rate of living donors who are women does not differ by race or ethnicity. The lower rate of LKD by men may reflect many factors, including higher rates of medical contraindications to donation (*e.g.*, diabetes and hypertension), sociocultural influences and expectations, and financial and economic considerations (57).

Geography

There is considerable regional variation in LDKT access and rates (6,39,58). At a surface level, and as depicted in Figure 3, LDKTs as a percentage of total kidney transplants

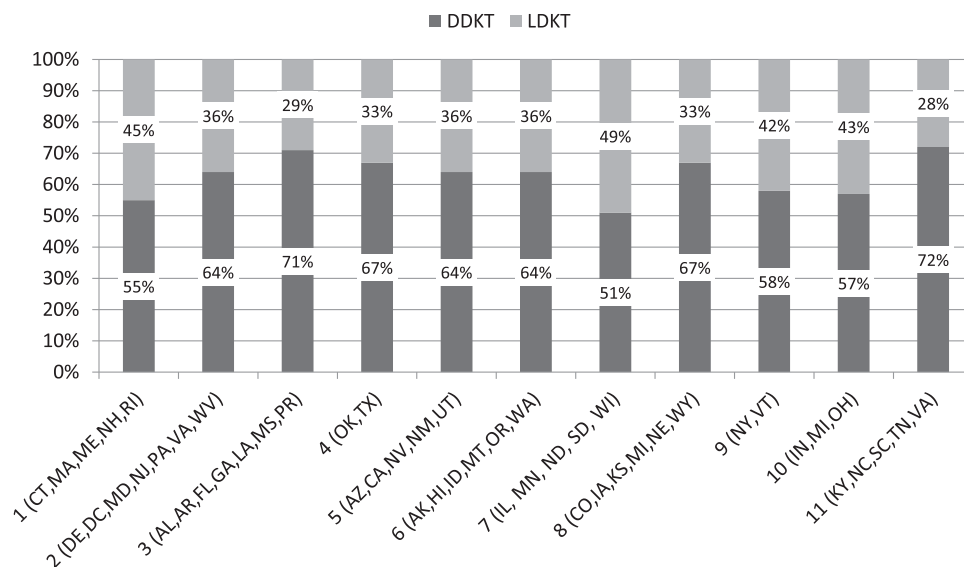


Figure 3. | Live donor versus deceased donor kidney transplantation as a percentage of total transplants, within UNOS region (United States, 2004–2013). DDKT, deceased donor kidney transplantation; LDKT, live donor kidney transplantation; UNOS, United Network for Organ Sharing.

vary considerably by United Network for Organ Sharing (UNOS) region in the United States (1). In more refined and sophisticated analyses, others have shown considerable geographic variability in LDKT rate by state and region, as well as population density, even after controlling for such factors as age, race/ethnicity, sex, and medical factors (6,58). In addition, adults residing greater distances from a transplant center and who are wait-listed in regions with shorter deceased donor waiting times are less likely to receive a LDKT (6,59). Moreover, patients have a higher likelihood of receiving a LDKT if they are referred to a transplant center that uses more unrelated living donors and that have active strategies for overcoming donor-recipient incompatibility (e.g., paired kidney donation, desensitization protocols) (60).

The annual number of living kidney donors increased in all UNOS regions before 2004; however, LKD stopped increasing in the majority of these regions within the last several years. The LKD decline has not been so pronounced in region 4 (Oklahoma, Texas), which has seen substantial growth in LDKT from KPD, and region 10 (Indiana, Michigan, Ohio).

Strategies to Reduce LDKT Disparities: Workgroup Recommendations

The mechanisms underlying LDKT disparities and LKD differences are unquestionably multifaceted and complex. Race and income, for instance, are known to intersect, with low-income blacks experiencing the largest decline in LKD, whereas LKD rates are highest among high-income blacks (47). Strategies that may prove efficacious in attenuating disparity in one area may have little effectiveness or, even worse, may exacerbate differences in another area. Innovative strategies have been developed to reduce racial/ethnic disparities in LDKT, particularly at the transplant center level. These include the use of transplant navigators (61,62), transplant educators making house calls to patients and their social network (63,64), recruiting and training living donor champions (65), and more effective communication with and education of patients and family members about LDKT and LKD (66–69). Although these strategies are promising, they have not yet been widely adopted and their utility with patients earlier in their disease process (*i.e.*, before transplant referral) has not yet been established. In addition, comparatively little research has been conducted on how best to overcome LDKT disparities rooted in socioeconomic status, age, sex, and geography.

Workgroup members recognized that addressing LDKT disparities and LKD differences must (1) begin before the patient's referral for transplant evaluation, (2) involve coordinated efforts among primary care physicians caring for patients with CKD, community nephrologists, dialysis providers, transplant professionals, patient organizations, and governmental agencies, and (3) be guided by empirical data that are based on both historical and current trends. Four core recommendations were generated by workgroup members and agreed upon by the general assembly of Consensus Conference participants (Table 1).

Recommendation 1: Remove Financial Disincentives to LKD

Eliminating financial disincentives to living donation is likely to have the broadest effect on reducing known

disparities in LDKT rates. Concern for out-of-pocket expenses, lost wages, job insecurity, and risk of insurability problems (health, life, disability) for living donors deters transplant candidates from pursuing LDKT and healthy adults from considering LKD. The National Living Donor Assistance Center (NLDAC) currently provides travel and lodging financial assistance to living donors who meet income eligibility criteria (70). Legislative authorization to expand the NLDAC to include reimbursement of lost wages (with an appropriate cap) and other direct expenses as well as the removal of financial means testing is an immediate priority to reduce the effects of class and racial disparities. Transplant patients, living donors, the general public, community nephrologists, and transplant providers all strongly support reimbursement of donation-related expenses to achieve financial neutrality for living donors (36,71–73), and at least 17 countries have launched pilot or national programs that include reimbursement for living donor lost wages (74).

The disparities workgroup supports the recommendations of Tushla *et al.* (44) from the Consensus Conference to achieve financial neutrality for living donors. These recommendations include legislative protection from job loss and insurance discrimination as a result of living donation as well as the creation of a toolkit to better educate transplant centers and potential living donors about the financial effect of donation and potential resources to mitigate cost. In addition, although many states offer tax deductions or credits for living donors who incurred expenses, many transplant providers and living donors are unaware that these programs exist. Tax relief programs have not affected rates of LDKT and LKD, perhaps because they require itemization of taxes (75,76). Because lower-income donors, who would benefit most from tax relief related to LKD expenses, are least likely to itemize tax returns, we recommend that all states consider establishing a tax credit (versus deduction) based on actual costs incurred by donors.

Recommendation 2: Implement Culturally Tailored, Community-Based LDKT/LKD Educational Programming at Multiple Stages of the Transplant Referral Process

Considering that LDKT yields superior outcomes to dialysis and deceased donor transplantation, we recommend that all key stakeholders work collaboratively to develop a strategy for ensuring optimal, culturally tailored LDKT education earlier in the patient's disease process. For instance, community nephrology practices, dialysis clinics, and transplant programs can work together to develop and offer a brief workshop for patients with stage 4 CKD and their family members to address treatment options, the benefits of LDKT, and living donation, including KPD. Exposure to a diverse (race/ethnicity, age, socioeconomic status) group of LDKT recipients and living donors in the context of these workshops may help activate patients and others in thinking about LDKT and LKD. Offering classes in participants' first language (or offering real-time language interpretation and translated written materials) and the inclusion of faith leaders may improve effectiveness and help to clarify religion-based concerns about LDKT and LKD. These community-based workshops can be recurring, offered a few times annually in different areas of a particular state or region to optimize educational

Table 1. Recommendations to reduce LDKT disparities and LKD differences	
Core Recommendations	Actionable Steps
(1) Remove financial disincentives to LKD	<p>Pursue legislative authorization to expand the National Living Donor Assistance Center to:</p> <ul style="list-style-type: none"> Include reimbursement of lost wages (with an appropriate cap) Include reimbursement of other direct expenses beyond lodging and travel Remove financial means testing <p>Pursue legislative protection from job loss and insurance (health, life, disability) discrimination as a result of living donation</p> <p>Pursue modification of existing state tax laws for living donation expenses from tax deductions (which require itemized tax returns) to tax credits</p> <p>Expand the availability of tax credits for living donation expenses to all US states and territories</p> <p>Develop a Living Donor Financial Tool Kit [Tushla <i>et al.</i> (45)] that includes guidance on financial effect of LKD and available financial resources, prepared in multiple languages and with respect for cultural differences</p>
(2) Implement culturally tailored, community-based LDKT/LKD educational programming at multiple stages of the transplant referral process	<p>Prepare a joint societies (<i>e.g.</i>, AST, ASTS, ASN, NKF) transplant education outreach curriculum that can be delivered to patients with stage 4 CKD and their family members before transplant referral and in the communities in which they live</p> <p>Transplant centers should evaluate their own program-level disparities in LDKT and implement quality improvement strategies to attenuate them</p> <p>Develop LDKT and LKD educational materials in multiple languages and with respect for cultural differences</p> <p>Integrate diverse (race/ethnicity, age, sex, SES) LDKT recipients and living donors into core LDKT education for transplant candidates</p> <p>To attenuate LDKT disparities, develop a strategy to conduct outreach to:</p> <ul style="list-style-type: none"> Faith leaders to help clarify religion-based misconceptions about LDKT/LKD Primary care physicians and nurses
(3) Engage a transplant liaison in community nephrology practices and dialysis clinics	<p>Form partnerships between transplant centers, dialysis corporations, independent dialysis clinics, and community nephrology practices to establish a transplant liaison program to:</p> <ul style="list-style-type: none"> Routinely educate providers about the benefits of LDKT, LKD processes and outcomes, and LDKT disparities Provide transplant education to transplant-eligible patients Facilitate navigation through and completion of transplant evaluation process
(4) Develop a research strategy to better understand LDKT disparities and LKD differences	<p>Hold a scientific summit on LDKT disparities in the next 2 yr to:</p> <ul style="list-style-type: none"> Better characterize the full range of LDKT disparities and LKD differences and their underlying mechanisms Identify promising and innovative efforts to reduce LDKT disparities at the individual, family, healthcare system, and community levels Establish research priorities on LDKT disparities Identify metrics to track progress in reducing LDKT disparities Identify the underlying mechanisms for the downward shift in LKD patterns Evaluate the effect of the new kidney allocation system on LDKT rates and disparities

LDKT, live donor kidney transplantation; LKD, living kidney donation; AST, American Society of Transplantation; ASTS, American Society of Transplant Surgeons; ASN, American Society of Nephrology; NKF, National Kidney Foundation; SES, socioeconomic status.

access for minority low-income, and rural patients. In addition, transplant centers should implement a more robust plan for educating primary care physicians and nurses about LDKT and LKD. These front-line providers have potential to improve patient trust in the transplant process, increase comfort with asking questions, demystify the referral pathway, and provide an impartial voice about LKD, which may attenuate LDKT disparities.

Recommendation 3: Engage a Transplant Liaison in Community Nephrology Practices and Dialysis Clinics

We recommend that nephrology practices and dialysis clinics have an identified transplant liaison to (1) ensure that staff and patients have up-to-date information about LDKT and LKD practices, national policies, disparities, and outcomes, and (2) facilitate a smooth transplant referral path, especially for those who may find navigating the complexities of the healthcare system more challenging and for those with cultural barriers. The transplant liaison could be a nurse, social worker, or community health educator, but the liaison must have current education and training about kidney transplantation and living donation. The role of the transplant liaison can be developed in collaboration with regional transplant programs and tailored to meet the specific educational needs of the staff and the particular demographics of the practice or clinic patient population. However, the goal would be to ensure that staff are optimally informed about LDKT/LKD so that they feel comfortable discussing these treatment options with patients and family members and to ensure that patients are informed of their LDKT option in accordance with the Medicare Improvement for Patients and Providers Act (Public Law 110-275), which provides for coverage of education to help Medicare beneficiaries understand all of their kidney disease treatment options. Transplant liaisons and navigators have been successfully utilized in some community nephrology practices and dialysis clinics and have been shown to be effective at engaging and educating patients, particularly those with known disparities, about LDKT (62,66). Research is needed to examine the most cost-effective strategies for integration of transplant liaisons into dialysis clinics and community nephrology practices.

Recommendation 4: Develop a Research Strategy to Better Understand LDKT Disparities and LKD Differences

In the last decade, there has been a substantial increase in health services and clinical research focused on disparities in kidney transplantation, spurred largely by a heightened focus on health disparities in general by government agencies, policy experts, ethicists, and researchers. Nevertheless, research on disparities in kidney transplantation—and LDKT in particular—is still in its early stages. To highlight the progress made to date, identify gaps, and develop a research agenda going forward, we recommend that a scientific summit on LDKT disparities be organized and held in the next 2 years. More scientific evidence is necessary to inform policy development and regulatory action at local, regional, and national levels that remove barriers to LDKT and LKD. Promising and innovative efforts to eliminate LDKT disparities and LKD differences must be identified and evaluated in a collaborative environment to facilitate rapid adoption by key stakeholders to accelerate access to

LDKT and LKD for disadvantaged populations. In addition, the summit can identify core metrics and a strategy for tracking progress in reducing LDKT disparities over the next decade.

Workgroup members acknowledged that although LDKT disparities and LKD differences have been identified, little is known about the mechanisms that contribute to their emergence and persistence. Increasing awareness about these disparities and differences among community nephrologists, dialysis providers, and transplant professionals is a critical first step and is the goal of this article. However, workgroup members emphasized the importance of a collaborative effort among all key stakeholders to develop a comprehensive strategy to eliminate LDKT disparities through coordinated education, policies that enhance access to LDKT and LKD, and a scientific agenda that facilitates the translation of innovative disparity-reducing strategies into practice.

Acknowledgments

Preparation of this manuscript was supported by the National Institute of Diabetes and Digestive and Kidney Diseases (Award Numbers R01-DK079665 and R01-DK085185 to J.R.R.).

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Diabetes and Digestive and Kidney Diseases or the National Institutes of Health.

The Consensus Conference Workgroup participants are as follows: Prabhakar Baliga (Medical University of South Carolina, Charleston, SC), Kristen Fischer (Sanford Transplant Center, Fargo, ND), Robert Gaston (University of Alabama, Birmingham, AL), Hassan Ibrahim (University of Minnesota, Minneapolis, MN), Bertram Kasiske (University of Minnesota, Minneapolis, MN), Didier Mandelbrot (University of Wisconsin, Madison, WI), Suzanne McGuire (University of California, Los Angeles, CA), Gwen McNatt (Northwestern University, Chicago, IL), Marc Melcher (Stanford University, Palo Alto, CA), Lainie Friedman Ross (University of Chicago, Chicago, IL), and Christie Thomas (University of Iowa, Iowa City, IA).

Disclosures

None.

References

1. Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR): *OPTN/SRTR 2012 Annual Data Report*, Rockville, MD, Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation, 2014
2. US Renal Data System: *2014 Annual Data Report: An Overview of the Epidemiology of Kidney Disease in the United States*, Bethesda, MD, National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2014
3. Purnell TS, Auguste P, Crews DC, Lamprea-Montealegre J, Olufade T, Greer R, Ephraim P, Sheu J, Kostecki D, Powe NR, Rabb H, Jaar B, Boulware LE: Comparison of life participation activities among adults treated by hemodialysis, peritoneal dialysis, and kidney transplantation: A systematic review. *Am J Kidney Dis* 62: 953–973, 2013
4. Ladin K, Rodrigue JR, Hanto DW: Framing disparities along the continuum of care from chronic kidney disease to transplantation: Barriers and interventions. *Am J Transplant* 9: 669–674, 2009
5. Gore JL, Danovitch GM, Litwin MS, Pham PT, Singer JS: Disparities in the utilization of live donor renal transplantation. *Am J Transplant* 9: 1124–1133, 2009

6. Axelrod DA, Dzebisashvili N, Schnitzler MA, Salvalaggio PR, Segev DL, Gentry SE, Tuttle-Newhall J, Lentine KL: The interplay of socioeconomic status, distance to center, and interdonor service area travel on kidney transplant access and outcomes. *Clin J Am Soc Nephrol* 5: 2276–2288, 2010
7. Gupta G, Unruh ML, Nolin TD, Hasley PB: Primary care of the renal transplant patient. *J Gen Intern Med* 25: 731–740, 2010
8. McGill RL, Ko TY: Transplantation and the primary care physician. *Adv Chronic Kidney Dis* 18: 433–438, 2011
9. Rodrigue JR, Schold JD, Mandelbrot DA: The decline in living kidney donation in the United States: Random variation or cause for concern? *Transplantation* 96: 767–773, 2013
10. LaPointe Rudow D, Hays R, Baliga P, Cohen DJ, Cooper M, Danovitch GM, Dew MA, Gordon EJ, Mandelbrot DA, McGuire S, Milton J, Moore DR, Morgievlch M, Schold JD, Segev DL, Serur D, Steiner RW, Tan JC, Waterman AD, Zavala EY, Rodrigue JR: Consensus conference on best practices in live kidney donation: recommendations to optimize education, access, and care. *Am J Transplant* 15: 914–922, 2015
11. Leichtman A, Abecassis M, Barr M, Charlton M, Cohen D, Confer D, Cooper M, Danovitch G, Davis C, Delmonico F, Dew MA, Garvey C, Gaston R, Gill J, Gillespie B, Ibrahim H, Jacobs C, Kahn J, Kasiske B, Kim J, Lentine K, Manyalich M, Medina-Pestana J, Merion R, Moxey-Mims M, Odum J, Opelz G, Orłowski J, Rizvi A, Roberts J, Segev D, Sledge T, Steiner R, Taler S, Textor S, Thiel G, Waterman A, Williams E, Wolfe R, Wynn J, Matas AJ; Living Kidney Donor Follow-Up Conference Writing Group: Living kidney donor follow-up: state-of-the-art and future directions, conference summary and recommendations. *Am J Transplant* 11: 2561–2568, 2011
12. Melcher ML, Blosser CD, Baxter-Lowe LA, Delmonico FL, Gentry SE, Leishman R, Knoll GA, Lefell MS, Leichtman AB, Mast DA, Nickerson PW, Reed EF, Rees MA, Rodrigue JR, Segev DL, Serur D, Tullius SG, Zavala EY, Feng S: Dynamic challenges inhibiting optimal adoption of kidney paired donation: Findings of a consensus conference. *Am J Transplant* 13: 851–860, 2013
13. Purnell TS, Hall YN, Boulware LE: Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. *Adv Chronic Kidney Dis* 19: 244–251, 2012
14. Waterman AD, Rodrigue JR, Purnell TS, Ladin K, Boulware LE: Addressing racial and ethnic disparities in live donor kidney transplantation: Priorities for research and intervention. *Semin Nephrol* 30: 90–98, 2010
15. Freeman MA, Myaskovsky L: An overview of disparities and interventions in pediatric kidney transplantation worldwide [published online ahead of print October 15, 2014]. *Pediatr Nephrol* doi:10.1007/s00467-014-2879-3
16. Purnell TS, Xu P, Leca N, Hall YN: Racial differences in determinants of live donor kidney transplantation in the United States. *Am J Transplant* 13: 1557–1565, 2013
17. Stolzmann KL, Bautista LE, Gangnon RE, McElroy JA, Becker BN, Remington PL: Trends in kidney transplantation rates and disparities. *J Natl Med Assoc* 99: 923–932, 2007
18. Gordon EJ, Ladner DP, Caicedo JC, Franklin J: Disparities in kidney transplant outcomes: A review. *Semin Nephrol* 30: 81–89, 2010
19. Hall YN, Choi AI, Xu P, O'Hare AM, Chertow GM: Racial ethnic differences in rates and determinants of deceased donor kidney transplantation. *J Am Soc Nephrol* 22: 743–751, 2011
20. Lentine KL, Schnitzler MA, Xiao H, Saab G, Salvalaggio PR, Axelrod D, Davis CL, Abbott KC, Brennan DC: Racial variation in medical outcomes among living kidney donors. *N Engl J Med* 363: 724–732, 2010
21. Muzaale AD, Massie AB, Wang MC, Montgomery RA, McBride MA, Wainright JL, Segev DL: Risk of end-stage renal disease following live kidney donation. *JAMA* 311: 579–586, 2014
22. Pollak MR, Genovese G, Friedman DJ: APOL1 and kidney disease. *Curr Opin Nephrol Hypertens* 21: 179–182, 2012
23. Lentine KL, Segev DL: Health outcomes among non-Caucasian living kidney donors: Knowns and unknowns. *Transpl Int* 26: 853–864, 2013
24. Cohen DM, Mittalhenkle A, Scott DL, Young CJ, Norman DJ: African American living-kidney donors should be screened for APOL1 risk alleles. *Transplantation* 92: 722–725, 2011
25. Tan JC, Dew MA, Rudow DL, Steiner RW, Woodle S, Hays R, Rodrigue JR, Segev DL: Best practices in education for providers and potential donors regarding living kidney donation. *Clin J Am Soc Nephrol* 10: 1670–1677, 2015
26. Navaneethan SD, Singh S: A systematic review of barriers in access to renal transplantation among African Americans in the United States. *Clin Transplant* 20: 769–775, 2006
27. Shilling LM, Norman ML, Chavin KD, Hildebrand LG, Lunsford SL, Martin MS, Milton JE, Smalls GR, Baliga PK: Healthcare professionals' perceptions of the barriers to living donor kidney transplantation among African Americans. *J Natl Med Assoc* 98: 834–840, 2006
28. Lunsford SL, Simpson KS, Chavin KD, Hildebrand LG, Miles LG, Shilling LM, Smalls GR, Baliga PK: Racial differences in coping with the need for kidney transplantation and willingness to ask for live organ donation. *Am J Kidney Dis* 47: 324–331, 2006
29. Siegel JT, Alvaro EM, Hohman ZP, Maurer D: "Can you spare an organ?": Exploring Hispanic Americans' willingness to discuss living organ donation with loved ones. *Health Commun* 26: 754–764, 2011
30. Boulware LE, Meoni LA, Fink NE, Parekh RS, Kao WH, Klag MJ, Powe NR: Preferences, knowledge, communication and patient-physician discussion of living kidney transplantation in African American families. *Am J Transplant* 5: 1503–1512, 2005
31. Rodrigue JR, Paek MJ, Egbuna O, Waterman AD, Schold JD, Pavlakis M, Mandelbrot DA: Readiness of wait-listed black patients to pursue live donor kidney transplant. *Prog Transplant* 24: 355–361, 2014
32. Rodrigue JR, Leishman R, Vishnevsky T, Evenson A, Mandelbrot DA: Concerns of ABO incompatible and crossmatch-positive potential donors and recipients about participating in kidney exchanges. *Clin Transplant* 29: 233–241, 2015
33. Boulware LE, Ratner LE, Sosa JA, Cooper LA, LaVeist TA, Powe NR: Determinants of willingness to donate living related and cadaveric organs: Identifying opportunities for intervention. *Transplantation* 73: 1683–1691, 2002
34. Robinson DH, Klammer SM, Perryman JP, Thompson NJ, Arriola KR: Understanding African American's religious beliefs and organ donation intentions. *J Relig Health* 53: 1857–1872, 2014
35. Siegel JT, Alvaro EM, Lac A, Crano WD, Dominick A: Intentions of becoming a living organ donor among Hispanics: A theory-based approach exploring differences between living and non-living organ donation. *J Health Commun* 13: 80–99, 2008
36. Tong A, Chapman JR, Wong G, Josephson MA, Craig JC: Public awareness and attitudes to living organ donation: Systematic review and integrative synthesis. *Transplantation* 96: 429–437, 2013
37. Lunsford SL, Simpson KS, Chavin KD, Menching KJ, Miles LG, Shilling LM, Smalls GR, Baliga PK: Racial disparities in living kidney donation: Is there a lack of willing donors or an excess of medically unsuitable candidates? *Transplantation* 82: 876–881, 2006
38. Bratton C, Chavin K, Baliga P: Racial disparities in organ donation and why. *Curr Opin Organ Transplant* 16: 243–249, 2011
39. Schold JD, Heaphy EL, Buccini LD, Poggio ED, Srinivas TR, Goldfarb DA, Flechner SM, Rodrigue JR, Thornton JD, Sehgal AR: Prominent impact of community risk factors on kidney transplant candidate processes and outcomes. *Am J Transplant* 13: 2374–2383, 2013
40. Gill JS, Gill J, Barnieh L, Dong J, Rose C, Johnston O, Tonelli M, Klarenbach S: Income of living kidney donors and the income difference between living kidney donors and their recipients in the United States. *Am J Transplant* 12: 3111–3118, 2012
41. Clarke KS, Klarenbach S, Vlaicu S, Yang RC, Garg AX; Donor Nephrectomy Outcomes Research (DONOR) Network: The direct and indirect economic costs incurred by living kidney donors—a systematic review. *Nephrol Dial Transplant* 21: 1952–1960, 2006
42. Dew MA, Jacobs CL: Psychosocial and socioeconomic issues facing the living kidney donor. *Adv Chronic Kidney Dis* 19: 237–243, 2012
43. Klarenbach S, Gill JS, Knoll G, Caulfield T, Boudville N, Prasad GV, Karpinski M, Storsley L, Treleaven D, Arnold J, Cuerden M, Jacobs P, Garg AX; Donor Nephrectomy Outcomes Research (DONOR) Network: Economic consequences incurred by living kidney donors: A Canadian multi-center prospective study. *Am J Transplant* 14: 916–922, 2014

44. Klarenbach S, Gill JS, Knoll G, Caulfield T, Boudville N, Prasad GV, Karpinski M, Storsley L, Treleaven D, Arnold J, Cuerden M, Jacobs P, Garg AX; Donor Nephrectomy Outcomes Research (DONOR) Network: Economic consequences incurred by living kidney donors: a Canadian multi-center prospective study. *Am J Transplant* 14: 916–922, 2014
45. Rodrigue JR, Cross NJ, Newman RC, Widows MR, Guenther RT, Kaplan B, Morgan MA, Howard RJ: Patient-reported outcomes for open versus laparoscopic living donor nephrectomy. *Prog Transplant* 16: 162–169, 2006
46. Rodrigue JR, Cross NJ, Newman RC, Widows MR, Guenther RT, Kaplan B, Morgan MA, Howard RJ: Patient-reported outcomes for open versus laparoscopic living donor nephrectomy. *Prog Transplant* 16: 162–169, 2006
47. Gill J, Dong J, Rose C, Johnston O, Landsberg D, Gill J: The effect of race and income on living kidney donation in the United States. *J Am Soc Nephrol* 24: 1872–1879, 2013
48. Gill J, Dong J, Gill J: Population income and longitudinal trends in living kidney donation in the United States. *J Am Soc Nephrol* 26: 201–207, 2015
49. Weng FL, Reese PP, Mulgaonkar S, Patel AM: Barriers to living donor kidney transplantation among black or older transplant candidates. *Clin J Am Soc Nephrol* 5: 2338–2347, 2010
50. Israni AK, Salkowski N, Gustafson S, Snyder JJ, Friedewald JJ, Formica RN, Wang X, Shteyn E, Cherikh W, Stewart D, Samana CJ, Chung A, Hart A, Kasiske BL: New national allocation policy for deceased donor kidneys in the United States and possible effect on patient outcomes. *J Am Soc Nephrol* 25: 1842–1848, 2014
51. Agarwal S, Oak N, Siddique J, Harland RC, Abbo ED: Changes in pediatric renal transplantation after implementation of the revised deceased donor kidney allocation policy. *Am J Transplant* 9: 1237–1242, 2009
52. Ahmadi AR, Lafranica JA, Claessens LA, Imamdin RM, IJzermans JN, Betjes MG, Dor FJ: Shifting paradigms in eligibility criteria for live kidney donation: A systematic review. *Kidney Int* 87: 31–45, 2015
53. Young A, Kim SJ, Speechley MR, Huang A, Knoll GA, Prasad GV, Treleaven D, Diamant M, Garg AX; Donor Nephrectomy Outcomes Research (DONOR) Network: Accepting kidneys from older living donors: Impact on transplant recipient outcomes. *Am J Transplant* 11: 743–750, 2011
54. Gillespie A, Hammer H, Kolenikov S, Polychronopoulou A, Ouzienko V, Obradovic Z, Urbanski MA, Browne T, Silva P: Sex differences and attitudes toward living donor kidney transplantation among urban black patients on hemodialysis. *Clin J Am Soc Nephrol* 9: 1764–1772, 2014
55. Gill JS, Hendren E, Dong J, Johnston O, Gill J: Differential association of body mass index with access to kidney transplantation in men and women. *Clin J Am Soc Nephrol* 9: 951–959, 2014
56. US Renal Data System: *USRDS 2013 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*, Bethesda, MD, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2013
57. Kayler LK, Meier-Kriesche HU, Punch JD, Campbell DA Jr, Leichtman AB, Magee JC, Rudich SM, Arenas JD, Merion RM: Gender imbalance in living donor renal transplantation. *Transplantation* 73: 248–252, 2002
58. Ashby VB, Kalbfleisch JD, Wolfe RA, Lin MJ, Port FK, Leichtman AB: Geographic variability in access to primary kidney transplantation in the United States, 1996–2005. *Am J Transplant* 7: 1412–1423, 2007
59. Davis AE, Mehrotra S, McElroy LM, Friedewald JJ, Skaro AI, Lapin B, Kang R, Holl JL, Abecassis MM, Ladner DP: The extent and predictors of waiting time geographic disparity in kidney transplantation in the United States. *Transplantation* 97: 1049–1057, 2014
60. Reese PP, Feldman HI, Bloom RD, Abt PL, Thomasson A, Shults J, Grossman R, Asch DA: Assessment of variation in live donor kidney transplantation across transplant centers in the United States. *Transplantation* 91: 1357–1363, 2011
61. Sullivan C, Leon JB, Sayre SS, Marbury M, Ivers M, Pencak JA, Bodziak KA, Hricik DE, Morrison EJ, Albert JM, Navaneethan SD, Reyes CM, Sehgal AR: Impact of navigators on completion of steps in the kidney transplant process: A randomized, controlled trial. *Clin J Am Soc Nephrol* 7: 1639–1645, 2012
62. Marlow NM, Simpson KN, Kazley AS, Balliet WE, Chavin KD, Baliga PK: Variations in coping stages for individuals with chronic kidney disease: Results from an exploratory study with patient navigators [published online ahead of print October 7, 2014]. *J Health Psychol* doi:10.1177/1359105314551776
63. Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ: Increasing live donor kidney transplantation: A randomized controlled trial of a home-based educational intervention. *Am J Transplant* 7: 394–401, 2007
64. Rodrigue JR, Paek MJ, Egbuna O, Waterman AD, Schold JD, Pavlakis M, Mandelbrot DA: Making house calls increases living donor inquiries and evaluations for blacks on the kidney transplant waiting list. *Transplantation* 98: 979–986, 2014
65. Garonzik-Wang JM, Berger JC, Ros RL, Kucirka LM, Deshpande NA, Boyarsky BJ, Montgomery RA, Hall EC, James NT, Segev DL: Live donor champion: Finding live kidney donors by separating the advocate from the patient. *Transplantation* 93: 1147–1150, 2012
66. Pradel FG, Suwannaprom P, Mullins CD, Sadler J, Bartlett ST: Short-term impact of an educational program promoting live donor kidney transplantation in dialysis centers. *Prog Transplant* 18: 263–272, 2008
67. Boulware LE, Hill-Briggs F, Kraus ES, Melancon JK, Falcone B, Ephraim PL, Jaar BG, Gimenez L, Choi M, Senga M, Kolotos M, Lewis-Boyer L, Cook C, Light L, DePasquale N, Noletto T, Powe NR: Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: A randomized controlled trial. *Am J Kidney Dis* 61: 476–486, 2013
68. Waterman AD, Robbins ML, Paiva AL, Peipert JD, Kynard-Amerson CS, Goalby CJ, Davis LA, Thein JL, Schenk EA, Baldwin KA, Skelton SL, Amoyal NR, Brick LA: Your Path to Transplant: A randomized controlled trial of a tailored computer education intervention to increase living donor kidney transplant. *BMC Nephrol* 15: 166, 2014
69. Gordon EJ, Reddy E, Gil S, Feinglass J, Rodde J, Abecassis MM, Caicedo JC: Culturally competent transplant program improves Hispanics' knowledge and attitudes about live kidney donation and transplant. *Prog Transplant* 24: 56–68, 2014
70. Warren PH, Gifford KA, Hong BA, Merion RM, Ojo AO: Development of the National Living Donor Assistance Center: Reducing financial disincentives to living organ donation. *Prog Transplant* 24: 76–81, 2014
71. Rodrigue JR, Crist K, Roberts JP, Freeman RB Jr, Merion RM, Reed AI: Stimulus for organ donation: A survey of the American Society of Transplant Surgeons membership. *Am J Transplant* 9: 2172–2176, 2009
72. Barnieh L, Klarenbach S, Gill JS, Caulfield T, Manns B: Attitudes toward strategies to increase organ donation: Views of the general public and health professionals. *Clin J Am Soc Nephrol* 7: 1956–1963, 2012
73. Tong A, Chapman JR, Wong G, Craig JC: Perspectives of transplant physicians and surgeons on reimbursement, compensation, and incentives for living kidney donors. *Am J Kidney Dis* 64: 622–632, 2014
74. Sickand M, Cuerden MS, Klarenbach SW, Ojo AO, Parikh CR, Boudville N, Garg AX; Donor Nephrectomy Outcomes Research Network: Reimbursing live organ donors for incurred non-medical expenses: A global perspective on policies and programs. *Am J Transplant* 9: 2825–2836, 2009
75. Lacetera N, Macis M, Stith SS: Removing financial barriers to organ and bone marrow donation: The effect of leave and tax legislation in the U.S. *J Health Econ* 33: 43–56, 2014
76. Venkataramani AS, Martin EG, Vijayan A, Wellen JR: The impact of tax policies on living organ donations in the United States. *Am J Transplant* 12: 2133–2140, 2012