

Meeting Report

Consensus Conference on Best Practices in Live Kidney Donation: Recommendations to Optimize Education, Access, and Care

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Live donor kidney transplantation is the best treatment option for most patients with late-stage chronic kidney disease; however, the rate of living kidney donation has declined in the United States. A consensus conference was held June 5–6, 2014 to identify best practices and knowledge gaps pertaining to live donor kidney transplantation and living kidney donation. Transplant professionals, patients, and other key stakeholders discussed processes for educating transplant candidates and potential living donors about living kidney donation; efficiencies in the living donor evaluation process; disparities in living donation; and financial and systemic barriers to living donation. We summarize the consensus recommendations for best practices in these educational and clinical domains, future research priorities, and possible public policy initiatives to remove barriers to living kidney donation.

Abbreviations: AST, American Society of Transplantation; CMS, Centers for Medicare and Medicaid Services; CoP, Community of Practice; EPC, Executive Planning Committee; ESRD, End-Stage Renal Disease; KPD, Kidney Paired Donation; LDKT, Live Donor Kidney Transplantation; LKD, Living Kidney Donation; MIPPA, Medicare Improvement for Patients and Providers Act; NLDAC, National Living Donor Assistance Center; SRTR, Scientific Registry of Transplant Recipients; UNOS, United Network for Organ Sharing

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Introduction

Live donor kidney transplantation (LDKT) is the best treatment for most patients with late-stage kidney disease, accounting for more than one-third of kidney transplants performed in the United States (1). Relative to deceased donor kidney transplantation and dialysis, LDKT yields superior graft and patient survival, improved quality of life, less dialysis exposure, and is more cost-effective (1–3). The transplant community strives to ensure that all transplant-eligible patients are fully informed about the option of LDKT, and that all modifiable barriers to living kidney donation (LKD) are eliminated for those willing and eligible to donate.

Recent trends suggest that the transplant community should reconsider its LDKT and LKD processes. First, there has been a decline in the annual number of living kidney donors in the United States (4), which is more pronounced for non-White, low-income, and older transplant candidates. It is notable that this decline has occurred during a period of a national economic downturn and increasing regulatory requirements. Second, living donors increasingly are unrelated, non-spousal donors from the patient’s extended social network (1). Third, LDKT as a proportion of total kidney transplants varies widely across transplant programs and regions, suggesting variable LDKT and LKD processes and practices (5). Finally, emerging data on the long-term medical and psychosocial outcomes of living donors have implications for how healthcare providers educate transplant candidates and potential donors (6–8).

To identify best practices and knowledge gaps pertaining to LKD that might influence LDKT access, a consensus conference was held on June 5–6, 2014 in Rosemont, Illinois. In this report, we summarize the conference findings and recommendations and conclude with an action plan to promote more effective LKD practices, advance the science of LKD, and implement policies that reduce financial and systemic barriers to LKD.

Methods

The Live Donor Community of Practice (CoP) of the American Society of Transplantation (AST) recognized the need to identify effective strategies to improve access to LDKT/LKD and improve LKD education and evaluation processes. A committee of CoP members identified five priority areas for best practices perceived to have high likelihood of influencing clinical practice when disseminated: Transplant Candidate LDKT Educational Processes; Potential Living Donor Educational Processes; Strategies to Optimize Efficiencies in LKD Evaluation; Strategies to Reduce Disparities in LKD; and Strategies to Reduce Systemic Barriers to LKD (Table 1). Committee members reviewed scientific literature and data from the Scientific Registry of Transplant Recipients (SRTR), polled 20 U.S. transplant programs with the highest LDKT volume/rate to identify center-level practices, surveyed AST members to identify potential best practices in core topic areas, and held a town hall meeting with 75 CoP members at the 2013 American Transplant Congress in Seattle, Washington. Three themes emerged: (1) the number of living donors has stopped increasing and has been declining, limiting LDKT access for many

patients; (2) novel strategies to remove barriers to LDKT and LKD are implemented at some, but not all, transplant programs; and (3) these strategies are not widely implemented nor have they been effectively disseminated, thus limiting their potential impact.

The CoP proposed a Consensus Conference on Best Practices in Live Kidney Donation, which was approved by the AST Board of Directors and subsequently co-sponsored by several organizations (see Disclosures). An Executive Planning Committee (EPC) identified 2 Leaders, 1 Facilitator, and 10–12 Members for each of 5 workgroups representing the core content areas identified previously, with careful consideration for diversity by profession, program size, geography, and area of expertise.

After the meeting participants were identified, significant pre-meeting activities began. Workgroups surveyed transplant professionals, reviewed scientific literature, reviewed clinical practices not reflected in empirical literature, examined international LKD policies, and held bi-weekly teleconferences to exchange information, deliberate, and debate. Each workgroup prepared a pre-conference document that: (i) summarized key issues discussed, (ii) identified practices with evidence of effectiveness and promising practices for which more information was needed, (iii) described potential problems in reaching consensus on best practices, and (iv) proposed an agenda for research and public policy priorities. Documents were distributed to participants before the conference.

Sixty-seven physicians, live donor and transplant coordinators, allied health professionals, administrators, researchers, policy experts, patient organization representatives, government agency officials, and patients (donors and a recipient) attended the conference. Workgroup breakout and cross-talk sessions occurred during the first day, with specific workgroup recommendations presented in a final plenary session, allowing ample time for discussion. Final clinical and educational, program, policy, and research recommendations are presented in Tables 2–5, and evolved from an assimilation of an evidence based review of the literature, surveys, and expert consensus.

Transplant Candidate LDKT Educational Processes

Healthcare professionals at transplant centers, dialysis centers, nephrology practices, and other settings have multiple opportunities, often over many years, to educate patients with CKD about the option of LDKT. In general, we recommend that healthcare professionals and centers serving patients with CKD develop a philosophical approach

Table 1: Consensus conference workgroups and objectives

Workgroups	Objectives
Transplant Candidate LDKT Educational Processes	Identify best practice strategies in educating transplant candidates about LDKT, including individual, family, and community outreach activities
Potential Living Donor Educational Processes	Identify best practice strategies in educating potential living donors, including individual, community outreach, commercial media, and solicitation activities
Strategies to Optimize Efficiencies in LKD Evaluation	Identify best practice processes to improve efficiencies in the LKD evaluation process
Strategies to Reduce Disparities in LKD	Identify disparities in LKD and best practice strategies to attenuate them
Strategies to Reduce Systemic Barriers to LKD	Develop specific improvement recommendations to reduce economic barriers to LKD at (a) the programmatic, payer, contracting and/or regulatory levels and (b) the individual donor level

Table 2: Educational and clinical recommendations from the Consensus Conference on Best Practices in Live Kidney Donation

Highest Priority

- LDKT education of patients with advanced stages of CKD should occur repeatedly throughout disease progression and transplantation processes (e.g. at evaluation, waiting list, re-evaluation)
- Educate general nephrologists and primary care physicians about LDKT so patients have access to transplant education earlier in the disease process
- Integrate essential components of LDKT content and processes across centers, to include comprehensive risk and benefit information about LKD, known fears or concerns about LKD, and opportunities for interaction between transplant candidates and LDKT recipients as well as with former living donors
- Create a LKD Financial Toolkit, which includes a summary of LKD financial risks, estimation of costs, available financial resources for the donor, state tax laws pertaining to donation, and how the Medicare Cost Report can best be optimized by programs

High Priority

- Develop a philosophical approach that LDKT is the best option for most transplant candidates and reflect this philosophy in educational processes
 - Provide more culturally-tailored LDKT education to racial/ethnic minority patients, with historically lower LDKT rates, and their support systems
 - Provide patients and their caregivers with training about how to identify and approach potential living donors
 - Increase awareness of the National Living Donor Assistance Center among providers, patients, and potential living donors
 - Develop a process to ensure that transplant and dialysis team members attain competency in living donation risks, methods for communicating risks and benefits, and ways to provide guidance to transplant candidates on effective and ethical approaches to engaging potential donors
 - Improve and expand the use of technology to better educate patients
 - Implement an independent, national clearinghouse (e.g. website) for the general public and potential donors
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Table 3: Program recommendations from the Consensus Conference on Best Practices in Live Kidney Donation

Highest Priority

- Hire dedicated living donor personnel, including a living donor coordinator and dedicated physician champion or director
- Participate in an active KPD program or refer potential incompatible pairs to programs that do

High Priority

- Develop a culture among members of the transplant center staff supporting the LKD program
 - Ensure that systems and personnel are in place to respond immediately and thoroughly to living donor inquiries
 - Create an expedited process for transplant candidates with potential LKDs who are at lower risk/lower morbidity or who may be able to receive a transplant pre-emptively
 - Carefully evaluate medically complex donors and inform donor candidates who are turned down because of these issues that they may have access to donation at programs with different eligibility criteria
 - Collect and systematically review living donor metrics to measure efficiencies
 - Create a quality improvement program to ensure ongoing evaluation and improvement of transplant candidate and living donor education about LDKT
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Table 4: Policy recommendations from the Consensus Conference on Best Practices in Live Kidney Donation

Highest Priority

- Actively pursue strategies and policies that achieve the goal of financial neutrality for living donors, within the framework of federal law
- Modify the National Living Donor Assistance Center to eliminate financial means testing and to include some reimbursement for living donor lost wages
- Develop and pass legislation that prohibits denial of coverage or increase in premiums of health, life or disability insurance for living donors
- Develop and pass legislation that ensures living donor surgery is considered a qualifying health condition under the Family Medical Leave Act

High Priority

- Improve and clarify CMS auditing of current transplant education practices within dialysis centers
- Expand OPTN policy pertaining to required educational elements for potential living donors, to include the higher risk of ESRD and pregnancy complications in kidney donors and additional psychosocial risks/benefits associated with donation and non-donation, as the evidence base evolves
- Clarify regulations about what dialysis centers must do to ensure compliance with CMS mandates regarding transplant education
- Inform transplant programs of program-specific LKD metrics (i.e. LDKTs performed, LDKT rate, proportion of living donors by key sociodemographic characteristics in which disparities exist, and utilization of the NLDAC program), in comparison to regional and national data
- Develop and disseminate uniform guidance to payers on coverage for living donor expenses
- Modify state tax laws to include a credit (vs. deduction) for living donation
- Create a mechanism to remove barriers to donation by non-residents

and practices that emphasize that LDKT is the best option for most transplant candidates.

Surveys of selected transplant programs by the workgroup found that programs spend a median of only 1 h educating patients about LDKT, with education occurring mostly during the transplant evaluation day. Given that LDKT is the best treatment for most patients with ESRD, it seems appropriate to increase time spent on LDKT education, to begin education earlier in the disease process (e.g. delivered by general nephrologists and dialysis providers), and to re-discuss LDKT at various time-points (e.g. CKD diagnosis, dialysis initiation, transplant evaluation, while on waiting list) (9). Different combinations of LDKT educational

content, amount of time spent, and delivery approaches have been evaluated with transplant candidates (10–12). These trials have demonstrated techniques that result in improved knowledge of and more positive attitudes about LDKT, successful completion of transplant evaluation, increased LKD evaluations, and/or higher LDKT rates.

We recommend integration of essential components to LDKT content and processes for transplant candidates across centers, providing comprehensive risk/benefit information about LDKT and LKD, addressing known fears or concerns about LDKT, providing candidates and their caregivers with training about how to find living donors, and facilitating interactions between transplant candidates

Table 5: Recommended research priorities from the Consensus Conference on Best Practices in Live Kidney Donation

Highest Priority

- Examine strategies to reduce financial barriers to living donation, with particular attention to the impact on current disparities in LDKT
- Evaluate the impact of strategies to strengthen partnerships between general nephrologists, dialysis providers, and transplant programs on LDKT education, access, disparities, and rates

High Priority

- Examine the effectiveness of different strategies to optimize informed decision-making about LDKT and living donation
- Evaluate quality improvement initiatives to optimize the donor evaluation process and experience, reduce delays, and increase participation in kidney paired donation

and LDKT recipients as well as with former living donors (13). Furthermore, transplant programs need consistent outreach to reach patients who may not otherwise be adequately informed about transplantation or LDKT options. Finally, we recommend transplant and nephrology professionals collaborate in developing better approaches to address the Medicare Improvement for Patients and Providers Act (MIPPA) of 2008 (Public Law 110–275), which provides for coverage of kidney disease education to help Medicare beneficiaries understand all of their renal replacement therapy options. A more coordinated effort is needed to promote optimal LDKT education, assure availability of education materials, and increase the oversight of current transplant education practices within dialysis centers.

Potential Living Donor Educational Processes

Current educational practices for living donors remain insufficient to ensure enough understanding to optimize informed consent, despite strengthened OPTN/UNOS policy and at least initial implementation of an independent living donor advocate (14). The Live Donor CoP has issued clarification on the role of the independent living donor advocate, which should provide guidance to transplant programs (15). Clinical practice should be improved to educate potential donors throughout the donation process. Effective educational approaches within the transplant field have incorporated motivational interviewing (16), culturally competent home visits and web-based tools (17,18), and support from family and friends (19). Approaches shown effective in other fields of practice should be considered, including patient education that incorporates health literacy best practices, adult learning theories, and the use of peer mentors, navigators, and family ambassadors (20–22). Educational strategies should incorporate guidance on interpretation of risk information as well as assessment of risk comprehension (23). Research is needed to further elucidate best practices in living donor education, identify effective integration of the role of the independent living donor advocate, and assess how to best utilize community-based resources. The optimal number of time points for education of potential living donors and formats for doing so remain to be determined.

Efforts are needed to ensure that transplant team members themselves attain competency in: the extant literature on LKD risks, methods of communication about LKD risks and benefits, and ways to provide guidance to transplant candidates on effective and ethical approaches to engaging potential donors. To assist professionals in obtaining competency, a national training program may provide the necessary knowledge and skills.

Although large-scale epidemiologic studies have better quantified the risks of death and ESRD following LKD (6,7,24), the precise interpretation of these important

studies is evolving (25,26). This is true with respect to the degree of risk of ESRD and death and whether risks for different donors may be too heterogeneous to be appropriately conveyed by a single risk estimate (23). Prospective and retrospective studies of other outcomes are needed.

OPTN policy pertaining to required disclosure during the informed consent process should be expanded to include education about an evolving understanding of the risk of ESRD in living donors compared with healthy non-donors (6,7,24–26). Additional elements to be included in the process of informed consent should be added, as the evidence base evolves, including: possible complications of pregnancy (27); factors influencing recipient benefits derived from LDKT; potential psychosocial benefits from donating and psychosocial risks from not donating (28–30); and factors that most strongly influence medical and psychosocial risk variability (6–8,16,23).

Quality public education about LKD is needed. Establishment of an independent clearinghouse, for example, a website for potential recipients and donors to learn about LDKT/LKD that is national, neutral, trustworthy, and standardized, could optimize public education. A central site, with content vetted via professional societies, would strengthen understanding and trust between community members, transplant candidates, and potential donors alike, with potential for reducing disparities in access as well.

Strategies to Optimize Efficiencies in LKD Evaluation

The efficiency of LKD programs and the evaluation process could be improved through several best practice strategies. High quality LKD programs routinely and regularly emphasize the importance of living donation to both transplant candidates and potential living donors. This requires a culture among members of the transplant staff supporting the LKD program and ensuring staff is well educated regarding all aspects of LKD.

Additionally, comfort level with LKD risk varies across programs; therefore, we recommend that programs carefully evaluate medically complex donors (e.g. with well-controlled hypertension or mild-moderate obesity) (31), and inform donor candidates who are turned down because of these issues that eligibility criteria vary across transplant programs (32). Whether programs are ethically obligated to inform turned-down donor candidates (and their intended recipients) that they may be acceptable donor candidates at some other programs warrants further discussion by the transplant community.

Programs must have a timely evaluation process for all donors. Further, we recommend that all programs participate in an active KPD program, or refer potential

incompatible pairs to programs that do. We further endorse the findings and recommendations of the 2012 KPD Consensus Conference (33).

Best practices in the LKD evaluation process must include resources solely devoted to the living donor program. These resources should include dedicated LKD personnel; specifically, a living donor coordinator and dedicated physician champion, protocols and personnel in place to respond immediately and thoroughly to potential donor inquires, and an infrastructure to collect and evaluate LKD evaluation performance. To achieve increased efficiency and maximize access to early LDKT, we recommend that programs maintain an expedited process for potential living donors whose intended recipient is at lower risk/lower morbidity (e.g. young with minimal comorbidities) or who may be able to receive a LDKT pre-emptively.

Areas within the LKD evaluation process that could benefit from additional research include identifying the optimal level of resources for achieving efficiencies in LKD evaluation, determining best utilization of transplant resources for the LKD program, evaluating the components and timeline of the LKD workup and evaluation process, and removing barriers (i.e. financial) to potential LKD.

Strategies to Reduce Disparities in LKD

Disparity was conceptualized by the workgroup as a difference in LKD access or rates that is unnecessary, avoidable, and modifiable (34). Of particular importance is identifying social, cultural, and economic factors that create or contribute to LDKT disparities based on race or ethnicity, income, age, and geography (5,35–38). More clinical, policy, and research attention should be focused on whether a shift in care practices could reduce or eliminate such disparities. Transplant program size, staffing, organization, resources, and philosophy may also contribute to LDKT and LKD disparities and should be further examined.

We identified several innovative strategies to provide more culturally-tailored LDKT education to minority patients with historically lower LDKT rates and their support systems, including making house calls (17), provider-guided discussions about LKD (10), transplant navigation assistance (12), culturally-competent web-based education (18), and education conducted in the patient's primary language (20). While some evidence suggests that these strategies may be effective in reducing racial/ethnic disparities in LDKT access, it is not clear whether disparities in LKD rates are attenuated since donor-specific data have not been reported. Nevertheless, we concluded that these strategies hold promise in reducing racial/ethnic disparities in LKD.

Expansion of the National Living Donor Assistance Center (NLDAC) (39) is likely to have the most immediate and substantial impact on attenuating financial disparities in

LKD, with strong potential to reduce geographic, gender and racial/ethnic disparities as well. NLDAC, with its current funding levels and benefits defined by Congress (Public Law 108–216), provides travel assistance to potential donors in which both donor and recipient meet financial eligibility guidelines. NLDAC prioritizes reimbursement when both the living donor's income and the recipient's income are each 300% or less of the federal poverty guidelines. Also, reimbursement of donor lost wages is specifically prohibited within the legislation authorizing NLDAC. We recommend that NLDAC allocation and provisions be modified to: (i) eliminate financial eligibility criteria of potential recipients and donors for program participation, and (ii) provide some standardized level of reimbursement for living donor lost wages, similar to what has been implemented in several other countries (e.g. the Netherlands, Canada, Australia, Israel). Additionally, a comprehensive strategy should be developed and implemented to increase awareness and improve utilization of NLDAC among providers and potential living donors.

Finally, we recommend that transplant program directors and administrators be provided with summary LKD metrics for their program, including (at a minimum) the number of LDKTs performed, the LDKT rate, the proportion of living donors by key sociodemographic characteristics in which disparities exist (e.g. race/ethnicity, sex, age), and utilization of the NLDAC program. Providing such targeted data, in comparison to regional and national data, may facilitate closer examination of practices and the development of quality improvement initiatives to optimize them and reduce disparities as appropriate.

Strategies to Reduce Systemic Barriers to LKD

Living donors are known to incur direct and indirect costs (40). Direct costs may include out-of-pocket expenses for travel, medications, co-payments, and dependent care. Indirect costs may include lost income and the depletion of leave time for the donor and/or caregiver. Job security and insurability may also be threatened. Collectively, these costs may pose a deterrent to LKD, exacerbate existing LKD disparities, and contribute to a decline in LKD (4).

We reached consensus that the transplant community must actively pursue strategies and policies that achieve the goal of financial neutrality for living donors, within the framework of federal law. We reviewed policies already in place in Canada, Australia, the Netherlands, and Israel, which all have mechanisms for reimbursement of donor expenses, including lost wages, in the absence of restrictive financial means testing. We recommend a national program be funded in the U.S. to offer living donors reimbursement for direct and indirect costs, including lost wages, without financially based exclusionary

criteria. This could be implemented within an expanded framework of the current NLDAC.

Given the range in guidance that transplant programs offer potential living donors about financial risks of donation, and the (limited) available resources to offset LKD financial burdens, we recommend the creation of a LKD Financial Toolkit. A Toolkit might include a summary of known financial risks, an equation model for helping living donors estimate direct and indirect costs, NLDAC information, a list of LD financial assistance, strategy support for discussion of LD recovery with employers, and describe state tax laws for LKD. Transplant programs and potential donors could use Toolkit resources to reduce economic uncertainty and impact for living donors. Some Toolkit strategies may help to attenuate donation costs (e.g. deductions for donors, paid leave for government employees), but these programs are complex, vary state by state, are underutilized, and are of unknown effectiveness (41). In addition, transplant programs might benefit from a detailed description of how the Medicare Cost Report can be optimized to reduce economic barriers to donation.

The need for other system improvements should be evaluated, including: provision of uniform guidance to third-party payers on coverage of LKD expenses; legislation to protect living donors from loss of or modifications to health, disability, and/or life insurance secondary to donation; provision of free legal counsel to living donors on matters pertaining to insurability and employment impact; legislation modifying state tax laws to include a credit (vs. deduction) for LKD, thus enabling all adults (including those who may not itemize taxes) to access this benefit; the systematic collection of data to better characterize the financial impact of donation; and creation of a mechanism to remove barriers to donation by non-residents that have met the pre-screening criteria of the transplant program.

Discussion

These Consensus Conference educational, clinical, policy, and research recommendations are intended to catalyze engagement by healthcare providers, researchers, professional and patient organizations, government agencies, and research funding entities to remove barriers to LKD for otherwise healthy and willing potential donors. The recent decline in LKD has important implications for those with ESRD awaiting transplantation. To the degree that modifiable barriers are contributing to this decline, the transplant community must work collaboratively to overcome them. While the EPC identified high priority recommendations for immediate action, conference participants considered all of the recommendations to be important and recognized that their implementation would require focused and sustained engagement by key stakeholders and that some would face significant challenges.

LDKT yields a health benefit for its intended recipients and substantial cost savings to society. However, the success of LDKT relies on more than the good intentions of a healthy adult. As a transplant community, we have an obligation and responsibility to ensure that the LKD option is presented to all potential donors and recipients consistently and informatively, to identify and eliminate disparities in LKD, and to develop systems to improve efficiencies in process while maintaining integrity and rigor. Stakeholders reached general consensus that all transplant programs should strive to achieve excellence along these dimensions. However, it is now necessary for the transplant and general nephrology societies, dialysis corporations, researchers, patient organizations, and governmental agencies to work collaboratively to develop centralized toolkits for the benefit of all stakeholders. A comprehensive dissemination plan was prepared by the EPC and approved by meeting attendees, which includes presentations to key stakeholders, engagement and collaboration across societies, monthly conference calls of the conference leadership, and a series of manuscripts by the individual workgroups.

Despite the best efforts of individual transplant programs, future optimization of LKD depends heavily on the implementation of national programs with sustainable benefits for both patients with ESRD and their potential living donors. There was overwhelming consensus that financial neutrality for living donors must be adopted as a core objective, both to remove financial burdens of LKD and to mitigate known racial/ethnic and income disparities in LDKT. Furthermore, the implementation of a sustainable national program that includes some reimbursement of lost wages and is inclusive of all living donors regardless of financial means was identified as an immediate goal, which if achieved would bring the United States in line with other countries that have implemented similar economic policies to support living donors.

There is an ongoing need for research to evaluate the effectiveness of educational strategies for potential living donors and their intended recipients as well as to ensure that approaches for improving systems do not have unintended negative consequences. The National Institutes of Health, the Agency for Healthcare Research and Quality, the Patient-Centered Outcomes Research Institute, and the Health Resources and Services Administration should play a critical role in fostering innovation, collaborative engagement, and scientific discovery for the benefit of all living donors and LDKT recipients.

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