Living-Donor Kidney Transplantation: Reducing Financial Barriers to Live Kidney Donation—Recommendations from a Consensus Conference

Lara Tushla, Dianne LaPointe Rudow, [...], and Rebecca Hays

Abstract

Live-donor kidney transplantation (LDKT) is the best treatment for eligible people with late-stage kidney disease. Despite this, living kidney donation rates have declined in the United States in recent years. A potential source of this decline is the financial impact on potential and actual living kidney donors (LKDs). Recent evidence indicates that the economic climate may be associated with the decline in LDKT and that there are nontrivial financial ramifications for some LKDs. In June 2014, the American Society of Transplantation's Live Donor Community of Practice convened a Consensus Conference on Best Practices in Live Kidney Donation. The conference included transplant professionals, patients, and other key stakeholders (with the financial support of 10 other organizations) and sought to identify best practices, knowledge gaps, and opportunities pertaining to living kidney donation. This workgroup was tasked with exploring systemic and financial barriers to living kidney donation. The workgroup reviewed literature that assessed the financial effect of living kidney donation, analyzed employment and insurance factors, discussed international models for addressing direct and indirect costs faced by LKDs, and summarized current available resources. The workgroup developed the following series of recommendations to reduce financial and systemic barriers and achieve financial neutrality for LKDs: (*1*) allocate resources for standardized reimbursement of LKDs' lost wages and incidental costs; (*2*) pass legislation to offer employment and insurability protections to LKDs; (*3*) create an LKD financial toolkit to provide standardized, vetted education to donors and providers about options to maximize donor coverage and minimize financial effect within the current climate; and (*4*) promote further research to identify systemic barriers to living donation and LDKT to ensure the creation of mitigation strategies.

Keywords: kidney transplantation, economic impact, kidney donation, organ transplant

Introduction

Live-donor kidney transplantation (LDKT) is the best treatment for eligible people with late-stage kidney disease. It yields better quality of life and clinical outcomes (including patient survival) than dialysis or deceased-donor kidney transplantation (1,2). Despite this, live kidney donation rates have declined in the United States in recent years. The Live Donor Community of Practice within the American Society of Transplantation, with the support of 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 best practices for live kidney donation and knowledge gaps that might influence live kidney donation and LDKT, with a focus on patient and donor education, evaluation efficiencies, and disparities and system barriers to living donation; the full meeting report is now available (3).

The financial effect of live kidney donation may be a source of stress for potential and actual living kidney donors (LKDs), as well as a cause for the decline in rates of LDKT. Recent evidence indicates that the economic climate may be associated with the decline in donation and that there are nontrivial financial ramifications for some LKDs (4,5). Perhaps a more fundamental concern is whether LKDs, who provide such a critical, life-altering gift, should be saddled with substantial financial penalties associated with the donation process. As such, this consensus conference workgroup explored systemic and financial barriers to LDKT in the United States and discussed strategies to help remove these barriers.

The conference attendees concluded that live kidney donation should be a financially neutral process: that is, while people cannot be provided with incentives to donate an organ as outlined in the National Organ Transplant Act of 1984 (6), they should also not suffer financial loss for making such a gift. In this section, we describe the workgroup's review of the literature estimating the financial effect of living kidney donation, summary of employment and insurance factors, resources available to minimize the financial effect of donation in the current environment, and review of alternative models (already enacted in such countries as Canada and Australia) that aim to reduce financial burdens (7–11). We describe the workgroup's resulting recommendations to: (*1*) allocate resources for standardized reimbursement of LKDs' lost wages and incidental costs; (*2*) pass legislation to offer employment and insurability protections to LKDs; (*3*) create an LKD financial toolkit to provide standardized, vetted education to donors and providers about options to maximize donor coverage and minimize financial effect within the current climate; and (*4*) promote further research to identify systemic barriers to living donation and LDKT to ensure the creation of mitigation strategies.

Background on Systemic Barriers to Living Kidney Donation

Evidence suggests that household income is associated with access to LDKT (5,12). On the basis of residence ZIP code and national registry data, both blacks and whites in lower-income areas were less likely to undergo LDKT (12–14). Since 2006, national living kidney donation rates have declined, a decrease some have ascribed in part to the downturn in the economic climate in the United States (1,12). Relatively compelling evidence indicates that socioeconomic status is an important factor in access to kidney transplantation (5,14,15). Because transplant candidates are likely to seek donors from

similar socioeconomic backgrounds, the lower rate of LDKT among patients with lower socioeconomic status may in part be due to the perceived or actual financial effect that donation may have on potential donors.

To date, LKD costs (and their effect on LKD decision-making) have not been systematically captured by the kidney transplant community. While most donation-related medical expenses are covered by the kidney transplant recipient's health insurance, the LKD may still incur costs. These may include direct out-of-pocket expenses (*i.e.,* travel, lodging, meals, parking, dependent care, and some uncovered medical expenses) and indirect costs (*i.e.,* lost wages, use of employer-sponsored paid time off, and effect of insurability or premium rates) (Table 1) (4). Total estimated costs for LKDs range from $0–$20,000, with an average of approximately $5000 (4,16,17). In a 2014 Canadian study, Klarenbach *et al.* reported that 96% of LKDs had experienced negative financial consequences from donation, with 47% reporting lost wages (16). Studies show that most LKDs incur a loss of about 1 month's household wages after donation (4,16–21). In the United States, limited studies have shown that up to 23% of donors incur financial hardship (18–21). LKDs may also have concerns about financial, employment, or insurance consequences. These concerns are not unrealistic in light of the recent economic downturn in the United States. Collectively, these findings show that living kidney donation is not financially neutral for many donors and these costs can affect decision-making for both kidney transplant candidates and potential LKDs.

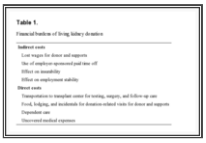

Table 1.

Financial burdens of living kidney donation

Despite the existing evidence, more is unknown than known about the financial consequences of living kidney donation. Potential financial considerations for LKDs (with limited empirical evidence) include any effect on life and health insurability (21). In addition, it is known that almost one fifth of current LKDs lack health insurance (22). At-risk donors are more likely to be black, have lower educational attainment, or not be a United States citizen (22). For these donors, out-of-pocket expenditures associated with medical care may be more extensive in the long term. This is particularly true in the current system in the United States, which lacks a payment system for provision of long-term follow-up care for past LKDs (as was recommended in a previous consensus conference) (23). These unknowns, as well as the limits in currently published data, led to a strong workgroup call for a research agenda that captures the effect of financial burdens on living kidney donation and the degree to which these function as barriers to LDKT (Table 2).

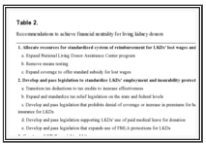

Table 2.

Recommendations to achieve financial neutrality for living kidney donors

Variability in Risk and in Approach: Employment, Lost Wages, Medical Costs, and Insurability

Workgroup members identified substantial variability in financial, employment, and insurability effect within the current United States system (Table 3), which offers neither a centralized place for education nor a safety net to reduce consequences. The theme across all these areas, in fact, was the variability and the lack of a consistent approach. Two primary aspects of employment affect the severity of living donation's financial consequences: the individual donor's employee benefits that cover lost wages and the donor's type of work (which may dictate duration of time off for recovery) (Table 3). In an unfortunate confluence, it is often the least financially stable donors who both are ineligible for paid time off (*e.g.,* manual laborers) and will require a longer recovery (*e.g.,* because of heavy-lifting restrictions). Plans for covering living expenses during recovery must be cobbled together, with the burdens of unpredictable options (and shortfalls) falling on the individual LKD, as is borne out in the available literature (4,21,22). The Family Medical Leave Act provides job security (not wage reimbursement) for some but not all LKDs, in that its protections are available only to full-time employees with 1-year tenure in larger companies (24). LKDs lack a consistent way to get paid during recovery, given that only a minority have the paid leave benefit afforded some government employees, including federal government, post office, and some public sector employees at the state and local levels (25). Other LKDs use vacation or sick time or short-term disability insurance benefits as available (which typically pay a portion of the regular wage). Finally, substantial groups of LKDs (including the self-employed, day laborers, contract employees, part-timers, and others who lack benefits) may be entirely without pay during surgical recovery.

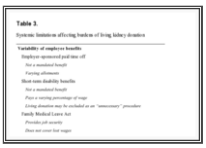

Table 3.

Systemic limitations affecting burdens of living kidney donation

LKDs sometimes incur direct medical expenses (Table 1). These vary among transplant centers and among payers (Table 3), as noted in robust workgroup discussion and at the consensus conference general assembly. Anecdotally, although there is general consensus that the Medicare Organ Acquisition Cost Center bundled-payment system covers the costs of living-donor evaluation and care, transplant center interpretation varies as to which living-donor services are billed through this mechanism, through Part B claims, or (unfortunately) directly to the donor. Transplant center interpretation, and thus practice, varies on coverage for routine health maintenance testing required for initial LKD work-up, postdonation medications, postdonation ambulatory checkups, and testing for or treatment of complications following donation. Coverage of LKD medical costs by the transplant recipient's private insurance (*e.g.,* employer group health plan) varies by payer and by contract. These factors affect LKDs' out-of-pocket costs. Additionally, although hospitalizations among past LKDs are low (*e.g.,* less than those for patients after appendectomy), they are still 11% at 3 years after donation (26).

Insurability problems after living kidney donation have also long been identified as a source of worry for donors, with the limited data showing that at least some donors have experienced negative consequences (Table 3) (27–29). As with other financial aspects, risk of insurability effect varies widely. Historically, this risk was mitigated by access to group health insurance coverage and associated portability protections under the Health Insurance Portability and Accountability Act of 1996 (30), with the self-insured and uninsured at higher risk for access problems. The Patient Protection and Affordable Care Act (31) has the potential to largely ameliorate barriers to health insurance after donation, although data are not yet available to explore the effect. However, there will be groups of people for whom the Affordable Care Act is not expected to provide accessible insurance or adequate access to care after donation (*i.e.,* those who cannot afford premiums, those who live in states that opted out of expanded Medicaid, undocumented immigrants). Albeit limited, data do indicate that living kidney donation may affect life insurability (27–29,32). Boyarsky and colleagues' single-center survey showed that of the 186 donors changing or initiating a life insurance application after donation, 46 (25%) reported difficulty (29). Workgroup participants agreed that access to insurance after donation is a frequent worry for potential LKDs and may function as a barrier.

Scattered Resources Fill Some Gaps: Health Resources and Services Administration–Funded Grant Program, Nonprofit Aide, and Tax Relief

Similar to inconsistencies in systems outlined above, the workgroup found that resources available to offset LKD financial burdens are scattered; these range from travel grants, to nonprofit emergency grants, to tax relief. Starting in 2007, the National Living Donor Assistance Center (NLDAC) (*via* a Health Resources and Services Administration grant) began offering grants to offset travel costs for living donors and their supports (33). From its inception through August 2013, NLDAC received 3918 applications and approved 89% of them. For those who donated (n=1816), the average reimbursement was $2700. Most donors (74%) said they would not have donated without NLDAC support. However, there are limits to the program. Reimbursement eligibility is means tested and is based on the incomes of both living donor and recipient. As such, although the program offers substantial help, only some LKDs can use it (nondirected donors have limited access because they cannot provide information about recipient income status), and it does not address lost wages, the largest burden for most living donors (16,17,21).

In addition, several organizations and foundations describe assistance programs for living organ donors' travel, housing, uncovered medical expenses, or lost wages. Although these nonprofits may offer invaluable help to the donors they reach, there is no central clearinghouse for donors, recipients, or health care providers to explain what may be available, who qualifies, and how to access those services. In the current setting, these resources may be inconsistently accessed or understood.

At the time of this writing, 35 states had passed legislation to offer tax deductions or credits, or other benefits, to living organ donors (34). These programs vary state by state, are underused, and are of unknown effectiveness. Fifteen of these living organ donor tax laws function as deductions (and therefore require the LKD to itemize taxes to use them), which may affect the utility of tax relief for low-income earners. Comprehensive reviews of these types of legislation found no statistically significant effect on organ donation for paid-leave legislation or for tax credits or deductions (34,35). However, the effect of this legislation on LKD financial burden (as opposed to donation rates) has not been studied.

Systems to Reduce LKD Financial Burden Elsewhere: International Models

The workgroup explored models built elsewhere to reduce systemic barriers to living kidney donation. Many countries have implemented systems to reduce out-of-pocket costs and minimize lost wages. These existing programs may be helpful in guiding development of future United States systems. Mechanisms vary, but the principle of living-donor financial neutrality is consistent. In their 2009 survey, Sickand *et al.* identified programs for wage

or incidental reimbursement of living donors in 21 countries, with lost income reimbursed in 17 (7). The minority of these (7) included means testing. Since 2009, other countries have implemented mechanisms for donor reimbursement, including lost wages, in the absence of restrictive financial means testing, including Canada, Australia, The Netherlands, and Israel. In addition, living donor reimbursement mechanisms are now in place throughout much of the European Union and in Saudi Arabia (7–11). As part of the consensus conference, transplant experts from Canada and Australia offered feedback on the implementation of their countries' living-donor reimbursement programs and highlighted early impressions that living organ donors will be positively affected by these programs (8,9).

Discussion and Recommendations

In short, LKDs are known to incur direct and indirect costs. Collectively, these costs may function as a barrier to living kidney donation, exacerbate existing LDKT, and contribute to a decline in living kidney donation. A systematic approach to reducing these barriers is lacking. Effectively addressing financial and systemic barriers to LDKT will require a multimodal approach.

Financial Neutrality as an Overarching Goal

The workgroup and the consensus conference general assembly reached an overwhelming consensus that financial neutrality for LKDs (within the framework of federal law) 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. There is general agreement in the transplant community that LKDs should not suffer financial consequences for a surgery that is medically unnecessary for their own health yet provides substantial benefit to the patient and to society (4,7,36–39). The following actionable steps are recommended to move this concept from a general values statement to a plan for LKD financial neutrality (Table 2).

Recommendation 1: Implement a Standardized System of Reimbursement for LKD Lost Wages and Incidental Costs

Implementation of a sustainable national program to include reimbursement of LKDs for direct and indirect costs (Table 1) (including a subsidy system for lost wages and potentially incidental expenses, such as dependent care), regardless of financial means, is an immediate goal. If achieved, this would bring the United States in line with other countries that have implemented similar economic policies to reduce burdens on LKDs. This could be implemented within an expanded framework of the current NLDAC.

Recommendation 2: Develop and Pass Legislation to Offer Employment and Insurability Protections to Living Donors

Given the degree to which tax benefits vary by state, as well as the variability in employment and insurability effects of living donation, the workgroup proposed a legislative and policy agenda centered on standardization, consistency, and discrimination protections for LKDs. Tax benefits should be expanded and standardized at both state and federal levels (and set as credits) to maximize use, especially for low-income donors. Legislation should be developed and passed to prohibit negative insurability consequences for LKDs (the Living Donor Protection Act is in early stages as of this writing, and it may include such provisions) (40). Legislation should be developed and passed to support LKD use of paid medical leave and to ensure that living kidney donation is a qualifying medical condition under the Family and Medical Leave Act.

Recommendation 3: Create a Living-Donor Financial Tool Kit

Given the range in guidance that transplant programs offer potential LKDs about financial risks of donation, along with the limited available resources to offset these burdens, we recommend creating a centralized resource to facilitate education and problem-solving. We recommend the development of a widely available, vetted LKD financial toolkit to guide health care professionals and prepare potential LKDs. At the time of this writing, a workgroup has been convened under the auspices of the American Society of Transplantation to develop a toolkit to reduce economic uncertainty and maximize service linkage to reduce effect on LKDs (41). In addition, transplant programs would benefit from uniform guidance in relation to billing options to maximize resources available to LKDs throughout the donation process (Table 4), to clarify contracting options with payers (Table 2), and to work toward standardized medical coverage for living donors across payers.

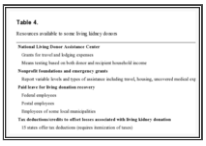

Table 4.

Resources available to some living kidney donors

Recommendation 4: A Research Agenda to Better Understand LKD Financial Barriers

Much is still unknown about the financial effect of living kidney donation and the degree to which it affects the LKD's experience, potential LKD decision-making, and rate of LDKT. Clearly, systematic collection of data to better characterize the financial consequence of donation is warranted; such data will improve understanding of indirect costs, any long-term medical costs, and any insurability problems associated with LDKT (Table 2). In turn, understanding the effect of these burdens on disparities in living kidney donation and access to LDKT could offer direction for ways to attenuate these differences. Finally, it would be useful to learn whether or which financial costs affect LKD satisfaction or serve as measurable disincentives to LDKT.

Conclusions

The workgroup was confounded by the lack of data about financial effects of living kidney donation and achieved early consensus that LKDs should suffer no financial consequences from their generosity. The next steps, as we saw them, are concrete and actionable ways to reduce financial burdens, with expansion of the existing NLDAC to remove means testing and to reimburse lost wages as a top priority. For effective movement, all kidney disease stakeholders must support mechanisms to allocate resources, enact basic civil protections, provide centralized education, and undertake research to better understand systemic barriers to LKDs and LDKT.

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