Live Donor Kidney Transplantation Consensus Conference:

Reducing Financial Barriers to Live Donation

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Live donor kidney transplantation is the best treatment for eligible people with end-stage renal disease. Unfortunately, living kidney donation rates have declined in the U.S. in recent years. To better understand this phenomenon, to identify opportunities to increase donation rates, and to promote best practices in live donor care, the American Society of Transplantation's Live Donor Community of Practice, with the support of 11 societies, convened the Consensus Conference on Best Practices in Live Kidney Donation in June 2014. The workgroup focused on reducing financial and systemic barriers to live donation, and had a multi-layered task: to review literature assessing the financial impact of living donation; to analyze employment and insurance factors; to learn from international models to reduce financial impact; and to summarize currently available resources. The group provided a series of clinical, programmatic, and policy recommendations to reduce financial and systemic barriers, with the overall goal of achieving financial neutrality for living kidney donations (LKD). In this article, we highlight systems-wide recommendations that would benefit from advocacy by nephrology social workers and their colleagues, and would ultimately improve clinical practice: policies to allocate resources to reduce donor financial burden, civil protections for donors, and a standardized, centralized financial resources clearinghouse.

INTRODUCTION

Live donor kidney transplantation (LDKT) is recognized as the best treatment for eligible people with end-stage renal disease because it results in better quality of life and clinical outcomes (USRDS, 2014). Since 2006, there has been a decrease in the rates of LDKT (OPTN/SRTR, 2014). The American Society of Transplantation's Live Donor Community of Practice convened, with the support of 11 societies, a Consensus Conference on Best Practices in Live Kidney Donation in 2014. Consensus Conference participants came from a variety of disciplines, regions, and transplant programs of varying sizes. The conference was divided into five workgroups, which included social workers and patients. The full meeting report is also available (LaPointe Rudow et al., 2015). One workgroup focused on reducing financial barriers to live kidney donation (Tushla, et al., 2015).

The workgroup reviewed literature related to financial impact of donation, summarized available resources for living kidney donors (LKD), highlighted gaps in the resources available in the U.S. system to offset costs and educate prospective donors, and discussed international models for addressing direct and indirect costs faced by LKDs. A series of recommendations were made to reduce financial and systemic barriers to living kidney donation with the overarching goal of achieving financial neutrality for LKDs.

FINANCIAL IMPACT

Real or perceived financial impacts of living kidney donation may be a factor in the decline of LDKT since 2006. To date, few studies have been conducted by the kidney transplant community on the effects of LKD costs and their impact on LKD decision making. However, significant data is beginning to emerge (Rodrigue et al., 2015).

While most donation-related medical expenses are covered by the transplant recipient's insurance provider, the donor may still incur costs. As summarized in Table 1, financial burdens may include direct out-of-pocket expenses (e.g., travel, housing, meals, parking, uncovered medical expenses) and indirect costs (e.g., lost wages, dependent care, use of employer-sponsored paid time off, effect on insurability or premium rates) (Dew & Jacobs, 2012). Total estimated costs for LKDs range from $0–20,000, with an average of approximately $5,000 (Clarke, Klarenbach, Vlaicu, Yang, & Garg; DONOR Network, 2006; Dew & Jacobs, 2012; Klarenbach et al., 2014; Rodrigue et al., 2015). These studies suggest that most LKDs lose about a month's household wages after donation, with donors experiencing financial hardship ranging from 23% (Dew & Jacobs, 2012) to 96% (Klarenbach et al., 2014). Rodrigue and colleagues (2015) studied donors in the evaluation process and found that 96% of donors noted at least one direct expense, averaging $523. Two-thirds of potential LKDs in this study reported missing work for donation-related evaluation. Twenty-seven percent of potential LKDs in this study reported lost wages averaging $691 (excluding paid time off). Caregivers for the potential donors reported a mean of $599 in lost wages.

In the post-donation phase of care, finances are equally challenging. The vast majority of LKDs (92%) had direct costs in at least one area, with a mean of $1,157. As to indirect costs, 36% of LKDs reported lost wages at an average of $4,578 when there were no paid benefits. Nineteen percent of caregivers reported lost wages at an average of $1,962 for caregivers (Rodrigue et al., 2016).

Collectively, these findings indicate that living kidney donation is not financially neutral for many donors. Rodrigue et al.

Table 1. Financial Burdens of Living Kidney Donation

Indirect Costs
Lost wages for donor and caregiver(s)
Use of employer sponsored paid time off (vacation/sick days)
Impact on insurability
Impact on employment stability
Dependent care
Direct Costs
Transportation to transplant center for testing, surgery, and follow-up care
Food, lodging, and incidentals for donation-related visits for donor and caregiver(s)
Uncovered medical expenses

(2016) showed that 89% of LKDs report a net financial loss in the 12 months post-donation, averaging $2,996. In fact, more is unknown than known about the financial consequences of living kidney donation. In 2012, Casagrande, Collins, Warren and Ommen, found that 23% of LKDs lack health insurance, which may cause this sub-group to have more out-of-pocket expenses in the long term. In addition, over the last decade, considering the economic downturn in the U.S., it is not unrealistic for LKDs to be concerned about the financial, employment, or insurance impact of donation.

VARIABILITY IN FINANCIAL RISK AND RESOURCES AVAILABLE TO REDUCE FINANCIAL IMPACT

Workgroup members identified substantial variability in work, financial, and insurability effect for live donors in the U.S. Furthermore, there is no centralized place for donors or healthcare providers to find reliable information about the limited resources to offset burdens to donor finances, employment, or insurability. Table 2 summarizes components of this variability that result in systemic barriers to live donation under the current U.S. system.

Two primary aspects of employment affect the intensity of the LKD's financial consequences: the degree to which the individual donor's employee benefits cover lost wages, and the donor's type of job, which may impact the duration of time off for recovery. In an unfortunate confluence, it is often the least financially stable donors who are both ineligible for paid time off (e.g., day laborers) and will require a long recovery (e.g., due to heavy-lifting restrictions in the immediate post-operative period). LKDs and their support systems are typically left cobbling together plans to cover living expenses during recovery with no reliable safety net (Davis & Cooper, 2010; Dew & Jacobs, 2012; Dew, Myaskovsky, Steel, & DiMartini, 2014).

Available benefits to cover lost wages vary. The Family Medical Leave Act (FMLA) provides job security (not wage reimbursement) for some, but not all, LKDs. Protections are only for full-time employees with one-year tenure in larger companies.

According to the U.S. Bureau of Labor Statistics (BLS) report (2013), in the private sector, 61% of employees have access to paid sick leave. The numbers are better for people in management and professional positions, with 88% receiving paid sick leave. Those with the lowest rates of paid sick leave were in construction at 36%. The availability of this benefit differs dramatically between full-time employees (74%), and their part-time counterparts who receive paid sick leave (24%). Perhaps not surprising is that of those receiving the lowest 10% of wages, only 22% have access to this benefit, while 86% of those in the highest 10% wage bracket do. Nearly all full-time state and local government employees receive paid sick leave according to the BLS. Some are even eligible for benefits specific to living kidney donation.

LKDs who earn paid time off typically use a combination of sick days, vacation time, and short-term disability insurance benefits to recover at least part of their lost wages. However, it should be recognized that a substantial group 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.

Direct medical expenses (Table 1) may be incurred by LKDs, varying by the recipient's insurance coverage and transplant center practice. For the vast majority of transplant recipients who are enrolled in Medicare at the time of transplant, the Medicare Organ Acquisition Cost Center's (OACC) bundled payment mechanism covers living donor evaluation, surgery, and post-donation care. As became clear in the Consensus Conference deliberations, transplant centers variably interpret how donor-related claims are billed through the OACC, through Part B claims, or directly to the donor. Complicating matters is the fact that private insurance coverage for living donor services varies by contract.

Over the years, there have been concerns about insurability for LKDs post-donation and there is literature to show that at

Table 2. Systemic Limitations Affecting Burdens of Living Kidney Donation

Variability of employee benefits

- Employer-sponsored paid time off
  - Not a mandated benefit
  - Varying allotments
- Short-term disability benefits
  - Not a mandated benefit
  - Pays a varying percentage of wages
  - Living donation may be excluded as an ”unnecessary” procedure
- Family Medical Leave Act
  - Provides job security
  - Does not cover lost wages
  - Employee qualifies after >/= 1 year, full-time, for an employer with >50 employees
  - Living donation may be excluded as a voluntary procedure
  - 11 states and Washington, D.C. expanded coverage

Variability of transplant center billing practice

- Medicare Organ Acquisition Cost Report LKD evaluation and care
- Medicare Part B interpretation for post-donation charges
- Private insurance and Medicare Advantage contract differences

Variability of risk for insurability problems

- Effect of Affordable Care Act (ACA)
  - Improved access to health insurance, generally
  - Limits to those expected to benefit from ACA include:
    - Those who cannot afford premiums (even with subsidies)
    - Those in states that did not participate in Expanded Medicaid
    - Undocumented immigrants
- Life insurance may be less predictable after living kidney donation
  - Eligibility problems
  - Premium increases

least some donors have experienced negative insurance consequences (Table 2) (Boyarsky et al., 2014; Spital & Jacobs, 2002; Yang et al., 2009). Traditionally, medical insurance vulnerability for LKDs has been mitigated by employer-sponsored insurance and the Health Insurance Portability and Accountability Act (HIPAA). The Patient Protection and Affordable Care Act (ACA) has the potential to ameliorate barriers to health insurance after donation for a portion of LKDs. However, there are people who will not benefit (e.g., those who cannot afford premiums, those in states that have not expanded Medicaid, undocumented immigrants). Life and disability insurance may still be impacted by serving as a living donor and certainly remains a concern.

SOME ISOLATED PROGRAMS MAY FILL SOME GAPS

As inconsistent as the systems are, so are the limited resources available to address the financial burdens to LKDs. Resources include: travel grants, emergency grants from nonprofit organizations, or tax relief. Unfortunately, a standardized, centralized place to locate and track these resources is lacking (see Table 3, which outlines resources available as of this writing).

NATIONAL LIVING DONOR ASSISTANCE CENTER (NLDAC)

Starting in 2007, NLDAC began offering grants to offset travel expenses for eligible living donors and their caregiver(s). In the first five years, NLDAC received nearly 4000 applications and were able to provide support to 89% of them, with an average reimbursement of $2700. However, in recent years, fewer than 10% of donors have availed themselves of the grant. For some donors, local to the transplant center, travel costs may not be a big worry. With eligibility linked to a means test for both the intended recipient and the donor, not all donors are able to get assistance. Finally, published data shows variability by center in grant usage, indicating an inconsistent referral pattern by transplant centers (Warren, Gifford, Hong, Merion, & Ojo, 2014).

Table 3. Resources Available to Some Living Kidney Donors

National Living Donor Assistance Center (NLDAC)
• Grants for travel and lodging expenses • Means testing, based on both donor and recipient household incomes
Nonprofit foundations and emergency grants
• Various levels and types of assistance, including travel, housing, uncovered medical expenses, lost wages
Paid leave for living donation recovery
• Federal employees • Postal employees • Employees of some local municipalities
Tax deductions/credits to offset losses associated with living kidney donation
• 15 states offer tax deductions (requires itemization of taxes) • 1 state offers credits

NONPROFIT ORGANIZATIONS

There are a few nonprofit organizations that help transplant recipients fundraise to offset expenses related to a transplant. Some do allow the funds to be used for living donor expenses as well. A few organizations offer living-donor-specific emergency grants.

TAX RELIEF

As of this writing, 35 states have tax deductions or credits available to living donors. According to Chatterjee, Venkataramani, Vijayan, Wellen, and Martin (2015), with one exception, there has been no observable effect of these policies on the rates of organ donation. The programs vary by state, are underused, and have been shown to have limited effect on living donor transplantation rates—though this does not speak to the value for past living donors, who have been able to use the deduction or credit (Chatterjee et al., 2015; Lacetera, Macis, & Stith, 2013; Matas & Hays, 2015; Venkataramani, Martin, Vijayan, & Wellen, 2012,). Those that function as tax deductions, typically require itemization, which may in turn limit their practical usefulness for low-income earners. For tax year 2005, an average of 36% of U.S. tax payers itemized (and only 18% of those earning less than $50,000) (Prante, 2007).

INTERNATIONAL MODELS

Many countries, including Canada, Australia, Israel, and the Netherlands, have developed systems-wide models to cover living donor costs, including systems to reimburse lost wages or provide a cost-of-living stipend during LKD recovery. In their 2009 survey, Sickand et al. identified 21 countries with programs, 17 of which provide reimbursement for lost income. During the Consensus Conference deliberations, experts from Australia and Canada weighed in on their respective countries' models, and participants deliberated their feasibility within the U.S. system.

DISCUSSION AND RECOMMENDATIONS

The workgroup identified recommendations to ameliorate financial burdens with the goal of financial neutrality for living donors (Table 4).

Recommendation 1: Standardized system for reimbursement of LKD lost wages.

Implementation of a standardized federal system to offset living donor costs, including a standard reimbursement amount for lost wages and excluding a means test, is a top priority. Clearly, there may be benefits to building from systems already in place in other countries (such as the Canadian wage reimbursement system). The simplest solution would be to expand the framework of the existing NLDAC program.

Status Update: Since the Consensus Conference, multiple meetings with stakeholders have occurred to lay groundwork for these ongoing discussions. This recommendation has been presented specifically to social work learners at the 2015 Society for Transplant Social Work Annual Meeting; the 2015 American Foundation for Donation and Transplantation Live Donor Course; and in a 2015 webinar for The Alliance.

Clearly, this recommendation is ambitious, requiring both a policy change and an allocation of resources to fund donor wage reimbursement. As such, advocacy by nephrology social workers, live donors, and transplant recipients will be essential to building momentum, and to effectively articulate the benefits of creating such a system.

Recommendation 2: Develop and pass legislation to offer employment and insurability protections for living donors.

The workgroup's legislative and policy agenda centered on standardization of employment-based benefits and support discrimination protections for living donors. Realistically, if reimbursement for lost wages is enacted, tax relief, and civil protections may become less essential. In the meantime, as a stopgap, tax benefits should be standardized (and set as credits) to maximize their use. Legislation should be developed and passed to prohibit negative insurability impact for living donors. Legislation should also 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 FMLA.

Status Update: The Living Donor Protection Act was introduced bicamerally in 2016. (Please see sidebar.) It will only gain traction as patients and their advocates (e.g., nephrology social workers) are able to describe its expected benefits.

Table 4. Recommendations to Achieve Financial Neutrality for Living Kidney Donors

1. Allocate resources for standardized system of reimbursement for LKD lost wages and incidentals

- Expand National Living Donor Assistance Center (NLDAC) program
- Remove means testing
- Expand to cover standard subsidy for lost wages

2. Develop and pass legislation to standardize LKD employment and insurability protections

- Transition tax deductions to tax credits to increase effectiveness
- Expand and standardize tax relief legislation on state and federal levels
- Develop and pass legislation that prohibits denial of coverage or increase in premiums for health, life, and disability insurance for LKDs
- Develop and pass legislation supporting LKD use of paid medical leave for donation
- Develop and pass legislation that expand utilization of FMLA protections for LKDs

3. Create a Living Kidney Donor Financial Tool Kit

- A summary of known financial risks
- An equation model for helping living LKDs estimate direct and indirect costs
- NLDAC service linkage
- A list of nonprofit sources of LKD financial assistance
- Strategy for LKD discussions with employers
- A description of state and federal laws directed at LKDs
- Uniform guidance for transplant centers in relation to billing options to maximize coverage of medical costs for LKDs:
  - Medicare Organ Acquisition Cost Report
  - Medicare Part B
  - Private insurance
- Uniform guidance to payers on coverage for LKD care

4. Research agenda

- Capture granular, systems-wide data on the financial effects of LKD
  - Indirect costs
  - Short- and long-term medical costs
    - Evaluation process
    - Routine follow-up
    - Coverage for complications
  - Insurability effect: coverage and rates
  - Effects on employment
- Effects on LKD caregivers during recovery period
- Capture data about variability in transplant center billing practices
- Characterize effect of financial and systemic barriers on potential LKD decision-making and rate of LDKT
- Characterize effect of finances on LKD satisfaction

Recommendation 3: Develop standardized, centralized education platform about financial impacts.

Given the range of financial guidance that transplant programs offer potential living donors, and the limited resources for financial assistance, conference participants recommended the creation of a widely available, vetted LKD financial toolkit, to guide healthcare professionals and prepare potential living donors. The toolkit resources could be used to reduce economic uncertainty and the impact for living donors. In addition, transplant programs would benefit from uniform guidance in relation to billing options to maximize resources available to LKDs, and clarify contracting options with payers (Table 4).

Status Update: The LKD Financial Toolkit has been completed, and will soon be released on the American Society of Transplantation (AST) website (myast.org).

In addition, *Transplant Program Guidelines for Best Practices in LKD Care* have been released by Consensus Conference leadership; these include recommendations about financial education for kidney donors. These will also be found at myast.org.

These toolkit elements can be used directly by patients, or used with a social worker in the clinic setting. In particular, a dynamic "cost estimator" may be a useful intervention tool.

Recommendation 4: A research agenda to better understand LKD financial battiers.

Much is still unknown about the financial impact of LKD, and the degree to which it affects LKD experience, potential LKD decision-making, and the rate of LDKT. Clearly, systematic collection of data to better characterize the financial impact of donation is warranted, including better understanding of indirect costs, any long-term medical costs, and any insurability problems associated with LDKT. In turn, understanding the impact of these burdens on disparities in LKD and access to LDKT could offer direction on 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.

Status Update: Some data is emerging to better characterize systemic barriers for LKDs, and the degree to which finances play a role. However, this is clearly an area ripe for exploration and deserving of social workers' unique viewpoints and expertise. As the clinicians most likely to be sorting through the impact of finances on donor readiness and decision-making, we encourage social workers to help design the research questions and data collection moving forward.

The Living Donor Protection Act (H.R. 4616/S. 2584) protects living donors by prohibiting insurance companies from denying or limiting life, disability and long term care insurance to living donors, and from charging higher premiums. It also protects donors' jobs by extending coverage under the Family and Medical Leave Act (FMLA). This bill currently has 29 sponsors in the House and six in the Senate. Please support NKF and donors by writing your legislators to ask them to sponsor this legislation.

CONCLUSIONS

The Consensus Conference process identified gaps in what is known about the finances of live donation, in methods of standardized information sharing for providers and potential donors, and in policy infrastructure for limiting systemic barriers. Clearly, living donors and nephrology social workers, as advocates and patient-centered clinicians trained in systems, will be instrumental in moving this field of study forward, and in achieving the policy changes recommended by the Consensus Conference. We must continue to clarify the current financial and insurability impacts of live donation, and build standardized websites to share findings and educate those considering living donation. In turn, skilled social work advocacy will be essential in building the systemic protections to limit financial, employment, and insurability impacts for donors, and in achieving resource allocation that will reduce financial burdens. Ultimately, the goal is that giving the "gift of life" won't cost an arm and a leg.

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