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Personal Viewpoint

Development of a Donor-Centered Approach to Risk Assessment: Rebalancing Nonmaleficence and Autonomy

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Living kidney donors are often excluded from the shared decision making and patient-centered models that are advocated in medical practice. Thresholds for acceptable risk vary between transplant centers, and between clinicians and donors. Although donor selection committees commonly focus on medical risks, potential donors also consider nonmedical risks and burdens, which may alter their assessment of an acceptable level of medical risk. Thus, transplant centers may encounter ethical tensions between nonmaleficence and respect for donor autonomy. A donor-centered model of risk assessment and risk reconciliation would integrate the donor's values and preferences in a shared decision about their eligibility to donate. This paper argues for shifting to a donor-centered model of risk assessment, and presents a research agenda to facilitate the greater participation of donors in their own evaluation and approval processes.

Abbreviations: ESRD, end-stage renal disease; OPTN, Organ Procurement and Transplantation Network

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Introduction

Over the last decade, the number of deceased donors has plateaued, while the number of patients in need of a kidney transplant has substantially increased to over 101 000 (1–3). The prevalence of end-stage renal disease (ESRD) in the United States is projected to increase by 4% annually (4), exacerbating the shortage of deceased donor organs. This mismatch between organ supply and number of transplant candidates has emerged as the major obstacle in the field. As a result, the transplant community will continue to rely on living donation to help address the need for kidney transplantation and to reduce the societal burden of ESRD.

The Organ Procurement and Transplantation Network's (OPTN) recent regulatory changes have enhanced risk disclosure to potential living kidney donors. Specifically, the OPTN's new guidelines establish minimal standards for living donor informed consent and medical evaluation, which should translate into better education and safety. However, the guidelines have not fundamentally altered the donor's limited role in the process that determines their eligibility to donate. Regulations that become too specific run the risk of transforming the donor informed consent and evaluation processes into regimented procedures. Centers may become transfixed on completing checklists to satisfy the OPTN requirements (5), instead of developing better methods to personalize the donor evaluation and approval process.

Unlike most other surgical procedures, donor nephrectomy exposes an individual to medical and surgical risks without the prospect of direct medical benefit. To ethically justify living donor nephrectomy, centers aim to minimize the medical risks to donors, emphasizing the principle of nonmaleficence and privileging medical expertise. This approach has contributed to a paternalistic approach to donor evaluation, which commonly excludes potential donors from the transplant team's discussion that determines eligibility to proceed with donation.

Given the increasing emphasis on patient shared decision-making (6,7), centers performing living donor kidney transplantation should consider donor-centered models of donor selection. A donor-centered approach would directly involve potential living donors and transplant providers in a joint decision-making process that takes into consideration a donor's specific long-term risks and a donor's tolerance for those risks in conjunction with her/his personal motivations for donating. A donor-centered approach

provides greater support for donors' autonomous decisions in a safe and ethical manner.

The following sections define the subset of donors for whom shared decision-making is likely to have the greatest impact and present arguments for incorporating shared decision making in donor evaluation. This paper includes suggestions for changing clinical practice and a research agenda to enhance living kidney donor autonomy.

Discretionary Donors

Most living donor consensus documents agree on the medical factors that increase the risk of donation but offer significantly different recommendations for the specific thresholds for inclusion or exclusion of donors (Table 1). These variations are due, in large part, to the lack of sufficient evidence to demonstrate the incremental long-term risks of these conditions. For example, both the United Network of Organ Sharing/OPTN and the European Best Practice Guidelines indicate that donors with diabetes should be excluded, whereas the UK guidelines allow diabetics to donate under certain circumstances (8–10). In the face of conflicting recommendations and inadequate data, transplant centers use variable criteria to accept medically complex living donors (11–14).

There are typically three groups of donors identified during the donor evaluation process: those who clearly meet all criteria to donate; those for whom there is a clear contra-indication to donation; and those for whom there may be a slightly increased risk of donation due to pre-existing medical conditions, such as obesity. This last group can be considered *medically complex donors*. Some potential donors who would be excluded due to medical concerns would no longer want to pursue donation if they were informed of the increased risk. Other medically complex donors that would be excluded from donation may be fully aware of the increased risk yet still want to donate; we will refer to this informed and willing group as *discretionary donors*. In the case of *discretionary donors*, the transplant team and the potential donor disagree about the acceptable level of risk to the donor. This paper focuses on discretionary donors as their situation highlights many of the limitations of the current evaluation system and justifies the adoption of donor-centered models to alter decisions about their ability to donate.

The Case for Shared Decision-Making in Living Kidney Donor Evaluation

Physicians balance respect for patient autonomy, or ''self-rule,'' against nonmaleficence, the obligation to avoid doing harm (15). The need to balance these two principles in living kidney donor evaluation is recognized by the Amsterdam Forum, which states that ''Donor consent and autonomy is [*sic*] necessary, but not sufficient, to proceed to kidney donation. Medical evaluation and concurrence is essential. Donor autonomy does not overrule medical judgment and decision-making'' (16).

Historically, the epistemic authority of the physician has enabled medical professionals to determine which risks and benefits were permissible for their patients. The focus on professional expertise has been bolstered by concerns that living donors might be coerced or unduly induced to donate, lack sufficient understanding of the relevant risks, or be too emotionally invested in their decision to appropriately weigh the risks of donation. The living kidney donor selection process still reflects this paternalistic approach to medical decision-making. Although living donors do engage in discussions about risks and benefits with members of the transplant team throughout the evaluation process, they are not invited to participate in the meeting that determines their eligibility. At the donor's request, many centers will occasionally re-discuss a medically complex donor who has been declined. However, other potential donors who wish to appeal the decision may not be aware that that they can seek referral to another transplant center or may not know how to do so.

With the decline in paternalism in health care, a new model for shared decision-making between the physician and patient has arisen (17–19). The Institute of Medicine defines patient-centered care as: ''Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions'' (20). In shared decision-making, a patient's preferences and values are integrated with the physician's expertise to develop a treatment plan. The use of shared decision-making models have been associated with improved patient satisfaction (21), knowledge (22), health outcomes (23,24), and medication adherence (24,25). Shared decision-making may also decrease costs of healthcare, due to lower healthcare utilization and an improved liability environment (26,27). While shared decision-making has been advocated for the recipient (18,28), application of this practice in donor evaluation has been largely overlooked.

Evidence about differences between donor and transplant center risk acceptance suggests that donors would welcome an approach that enhances their dialogue with donor review committees. In a single-center survey, potential donors were willing to accept significantly higher risks of hypertension, cardiovascular disease and ESRD than would transplant professionals (29). Notably, potential donors were also more tolerant of uncertainty, and were nearly twice as likely as transplant professionals to believe that living donation should be permitted in the face of uncertain long-term risks (29).

Adoption of a donor-centered approach could offer a principled way to redefine the range of potential benefits

Table 1: Recommendations for management of risks to living kidney donor

	UNOS guidelines (current) (8)	European Renal Best Practice Guidelines (2014) (9)	Amsterdam Forum (2005) (48)	UK donor evaluation guidelines (2011) (10)	Australia guidelines (2010) (49–54)
Hypertension	*Decline* • ''Uncontrollable'' hypertension • Hypertension with end stage organ damage	*Allow* • Ambulatory blood pressure <130/85 on a maximum of 2 medications *Decline* • Hypertensive end organ damage	*Decline* • Ambulatory blood pressure >140/90 *Consider low-risk/acceptable* • Hypertension is easily controlled and if >50 years old, GFR >80 mL/min, urine albumin <30 mg/24 h	*Allow* • Mild–moderate hypertension controlled with 1–2 medications if no significant end organ damage *Relative contraindication* • Hypertensive end-organ damage • Poorly controlled hypertension • Hypertension requiring >2 medications for control	*Decline* • Hypertensive end-organ damage • Hypertension requiring >2 medications • Hypertension with other cardiovascular risk factors
Diabetes	*Decline* • Diabetes	*Decline* • Diabetes, except in ''exceptional circumstances''	*Decline* • Diabetes • Fasting glucose ≥ 126 mg/dL on 2 occasions	*Consider* • Diabetes without end-organ damage and optimally managed cardiovascular risk factors	*Decline* • Diabetes • Past history of gestational diabetes
Impaired glucose tolerance	–	*''Not an absolute contraindication to donation''*	*Decline* • 2-hr oral glucose tolerance test > 11.1 mmol/L	–	*Decline* • 2-h oral glucose tolerance test ≥ 7.8 mmol/L
Obesity	–	*Decline* • Body mass index >35 kg/m^2	*Discourage* • Body mass index >35 kg/m^2	*Discourage* • Body mass index >35 kg/m^2	*Relative contraindication* • Body mass index >30 kg/m^2 *Decline* • Body mass index >30 kg/m^2 and another risk factor for chronic kidney disease
Dyslipidemia	–	–	*Consider as a risk factor*	–	–
Cardiovascular disease	–	–	–	*''Low threshold'' to exclude* • Cardiovascular disease	
Renal function	–	–	*Generally exclude* GFR <80 mL/min/1.73 m^2 • GFR >2 standard deviations below normal	*Recommended minimum* • Predicted GFR > 375 mL/min/1.73 m^2 at age 80	*Preferable not to accept* • GFR <80 mL/min/1.73 m^2

(*Continued*)

Table 1: Continued

	UNOS guidelines (current) (8)	European Renal Best Practice Guidelines (2014) (9)	Amsterdam Forum (2005) (48)	UK donor evaluation guidelines (2011) (10)	Australia guidelines (2010) (49–54)
Proteinuria	–	*Decline* • Urine protein >300 mg/24 h • Spot urine albumin/creatinine ratio >30 mg/mmol *High risk donors* • Urine protein 30–300 mg/24 h over 3 months	*Decline* • Urine protein >300 mg/24 h	*Usually contraindication* • Albumin/creatinine ratio >30 mg/mmol • Protein/creatinine ratio >50 mg/mmol • Urine protein >300 mg/24 h	*Usually contraindication* • Urine protein >300 mg/24 h • Spot urine protein/creatinine ratio >30 mg/mmol *Relative contraindication* • Urine protein <300 mg/24 h if another clinical or laboratory abnormality is present
Microalbuminuria	–	–	*Value ''has not been determined''*	*Significance ''has not been fully evaluated''* *Requires ''careful evaluation and counseling''* • Albumin/creatinine ratio 3.5–30 mg/mmol • Urine protein of 150–300 mg/24 h • Protein/creatinine ratio 15–30 mg/mmol	*Relative contraindication* • Urine albumin >30 mg/24 h • Albumin/creatinine ratio >2.5 mg/mmol
Hematuria	–	*Decline* • Persistent hematuria of glomerular origin (with the possible exception of thin basement membrane disease)	*Decline* • Persistent hematuria unless urine cytology and urologic workup are performed	*Decline* • Glomerular pathology (with the possible exception of thin basement membrane disease) • Persistent hematuria unless urologic workup performed	*''Needs further investigation to determine if this is clinically significant''*
Pyuria	–	–	–	*Decline* • Unless due to a reversible cause	–
Stone disease	–	–	*Decline* • Nephrocalcinosis or bilateral stone disease, with stone types that have high recurrence rates *Consider* • Current single stone <1.5 cm or removable • No hyperalciuria, hyperuricemia, metabolic acidosis, cystinuria, hyperoxaluria, urinary tract infection, multiple stones, nephrocalcinosis	*Consider* • Previous or current small renal calculus, if no metabolic abnormality	–

Table 1: Continued

	UNOS guidelines (current) (8)	European Renal Best Practice Guidelines (2014) (9)	Amsterdam Forum (2005) (48)	UK donor evaluation guidelines (2011) (10)	Australia guidelines (2010) (49–54)
Malignancy	*Decline* • Active malignancy • Incompletely treated malignancy	–	*Decline* • History of melanoma, testicular cancer, renal cell carcinoma, choriocarcinoma, hematological malignancy, bronchial cancer, breast cancer, or monoclonal gammopathy *Consider* • Prior treatment malignancy did not decrease renal reserve, increase the risk of ESRD, or increased the operative risk • The cancer is curable and potential transmission can be ''reasonably excluded''	*Consider* • Certain types of successfully treated low-grade malignancies	–
Psychiatric conditions	*Decline* • Psychiatric condition requiring treatment before donation • Evidence of suicidality	–	–	–	–
Overall	–	*Decline* • >1 risk factor	–	–	–

to the donor that are taken into account during the evaluation process. In particular, the significance of psychosocial and financial benefits of donation often has been overlooked (30). For example, while donors may view donation to close relatives, particularly spouses, as providing self-benefit (31,32), this perception is not always endorsed by the transplant community. Some transplant centers implicitly recognize the nonmedical benefits to a donor by allowing donors to accept greater risks when donors have close relationships to their intended recipient (e.g. allowing a medically complex individual to donate to a child but not to a work colleague) (11). Other transplant centers do not adjust acceptable risk levels on this basis. In fact, some guidelines explicitly direct transplant centers to treat these psychosocial motivations as irrelevant: ''the relationship between the donor and the recipient should not alter the level of acceptable risk'' (33).

A donor-centered approach may improve donor satisfaction with the evaluation process. The current medical-centered approach to decision-making can exacerbate the lack of control that potential donors experience about their ability to respond to a loved one's illness, a feeling that is common among family and caregivers of patients with chronic illnesses (34,35). Evidence to support this notion is that living donors have cited the difficulty of not knowing how long a loved one will need to wait for a deceased organ donor as a motivation for donation (36).

A shared decision-making model is especially well suited to donors. Younger and better-educated patients are open to shared decision-making models (37,38), both characteristics common among potential donors. Selecting a treatment option is especially important when there is scientific uncertainty or disagreement about a treatment's superiority (39). When there is no clear best treatment, selecting between the options should rely less on professional expertise, and more on an individual's preferences for various health states and set of tradeoffs between short- and long-term risk and benefits. The uncertainty surrounding the impact of specific medical states on donor outcomes suggests an important role for greater donor involvement in decision-making.

Implications for Clinical Practice

A donor-centered approach to evaluation does not mean that donor preferences should always take precedence over duties to protect the donor from unreasonable risk. Some conditions should be absolute contraindications to donation. Transplant centers should remain cognizant of the potential impact of poor donor outcomes on center certification status and public opinions about living donation. Moreover, professional standards and provider conscience should continue to play a role in decisions to refuse a discretionary donor. However, centers should do so only after offering the potential donor the opportunity to engage in a shared decision-making process. A donor-centered approach to declining a donor would entail informing the donor about the extent to which medical uncertainty persists. Discretionary donors should be advised that other centers may use different criteria for accepting living donors.

A donor-centered approach does not necessarily require adjustments to the magnitude of risk/benefit ratio that a center deems appropriate for ruling out potential donors. We believe that any additional risk incurred by a donor needs to be balanced with a potential benefit to the donor. However, a donor-centered approach would likely require the transplant center to expand the range of potential benefits (e.g. emotional and practical) that it incorporates into its risk/benefit calculation, thus potentially counterbalancing increased medical risks that discretionary donors would be undertaking. Under a donor-centered approach, a 47-year-old mother with hypertension controlled by two antihypertensive medications and mild depression due to her daughter's renal disease might be allowed to pursue donation if her quality of life might be greatly improved and caretaking burdens reduced by donation. A husband with microalbuminuria who has gone into debt because his wife has been unable to work while on dialysis might also be allowed to donate. A donor-centered approach would allow a transplant center to accept both the mother's and the husband's reasons as suitable motivations to justify the incremental risk to discretionary donors who would be otherwise declined under the current approach to donor evaluation.

Adoption of a donor-centered approach could change many aspects of the donor evaluation process. The following hypothetical evaluation scenario incorporates a variety of innovations to enhance the living donor's ability to convey their motivations and values directly to the transplant team. In certain circumstances, discretionary donors would be allowed to attend the donor selection committee meetings, where they would present their reasons for donating and hear (and respond to) the concerns raised by the transplant team. Potential discretionary donors who did not wish to attend the meeting in person would be offered the opportunity to video-record, audio-record, or write a statement describing their commitment to donation. The donor selection committee would review the statement prior to making a final determination of the discretionary donor's candidacy. The potential donor's attendance at the donor selection committee meetings or personal statement would be optional. Some potential donors, particularly those who are considering opting out of donation, may not be comfortable describing their motivation to donate. In such cases, the evaluation process would proceed without direct participation from the potential donor. If a discretionary donor was declined, he or she would be advised of the availability of an expedited ''second opinion process'' at another center.

While some potential donors ask their independent living donor advocate to facilitate communication with a former donor, others are unaware of this option. To enhance the donor education process, all living donors could be invited to share their experiences, via written narratives, with the center's subsequent potential donors. The narratives could be shared on a website, distributed to all potential donors, or made available in the transplant clinic waiting room. Transplant centers can also develop structured programs to enable potential donors to meet with former living donors.

Each of these clinical practice changes should be evaluated to assess the impact on donor satisfaction with the evaluation and selection process, transplant team efficiency in decision-making, and donor outcomes. Centers could also report the number of discretionary donors they accepted during the reporting period. Prospective donors and recipients should use this information not only to interpret the transplant center's statistics, but also as a metric to determine the extent to which a center has adopted a donor-centered approach to donor evaluation.

Research Agenda

We identified five avenues for further epidemiological research, improvements in risk communication, and enhancements to clinical practice. Foreseeable obstacles and possible solutions to each research agenda item are outlined in Table 2. This line of inquiry does not need to precede adoption of a donor-centered approach to the evaluation of living kidney donors, but is instead designed to generate data and methods to optimize its implementation. Well-conducted studies could inform the empirical and ethical foundations for re-defining and re-structuring the donor approval process.

Improve medical risk calculation

Large-scale epidemiological studies are necessary to determine how the potential medical contraindications to donation (Table 1) would affect a discretionary donor's risk of developing ESRD. Determination of the relative risk to discretionary donors would reduce the uncertainty about the long-term health effects of donation, thus informing transplant centers' current thresholds for donor exclusion and acceptability. For example, studies report that donors have a relative risk of ESRD that is greater than their baseline, but still lower than that of the general population (40,41). These studies have enhanced the transplant team's ability to provide potential donors with an accurate assessment of their absolute and relative lifetime risk of developing ESRD, by a variety of factors (e.g. age and race/ethnicity, socioeconomic status) compared to the general population. Other factors may likewise be associated with increased long-term risks for the discretionary donor.

Establishing risk levels and maximum acceptable thresholds for a specific abnormality (e.g. well-controlled hypertension) is a first step in improving risk assessment for living donors. Ideally, a single measure would summarize the cumulative impact of multiple risk factors such as age and family history on the lifetime risk of developing ESRD, analogous to the Kidney Donor Profile Index Calculator to

Table 2: A research agenda for donor-centered risk assessment, with selected foreseeable obstacles and potential solutions

Research agenda item	Foreseeable obstacle	Potential solution
Improve medical risk calculation	There may be low statistical power due the small number of living donors with ESRD or other documented negative outcomes	Analyses could be performed using data pooled from multiple transplant centers or countries
Evaluate broader motivations for donating	Donors may be hesitant to share motivations or concerns for fear of affecting their donor eligibility status	All providers/clinicians involved in the donor evaluation process can emphasize the importance of understanding all the donor's motivations and concerns to ensure that they can provide adequate support for the donor
Enhance risk communication	Alternative methods of risk communication or framing of risks may confuse potential donors, particularly if members of the transplant team use different terms or frames	Members of the transplant team could agree on a method of communicating and framing risks to donors; educational materials and consent documentation should be modified accordingly
Understand donor risk acceptance	Studies may further burden potential donors during already lengthy evaluation workup days	Researchers can accordingly develop some instruments that do not require the donor to be at the clinic to complete them (e.g. by telephone, text message, by mail, or online)
Assess transplant center practices	Patient care commitments may limit transplant centers' ability to complete surveys about their evaluation practices or systematically collect relevant data	Centers that participate in surveys about their evaluation practices for medically complex and discretionary donors could be eligible to apply for pilot funding to implement a donor-centered model of risk assessment

evaluate the relative risk of posttransplant graft failure from a deceased donor (42). The transplant community could develop a validated living donor ESRD risk calculator; such efforts are already in progress. A living donor ESRD risk calculator would help both transplant teams and potential donors quantify and contextualize the incremental risk for discretionary donors (43).

Evaluate broader motivations for donating

Understanding an individual's motivation to donate is a critical feature of a donor-centered approach to donor evaluation. While much work has documented reasons for donating (31,32), Allen et al's (30) article on the nonmedical effects of being declined as a donor highlights the ways in which the assessment of a donor's motivations should be broadened. For example, centers could assess in greater detail the impact of the intended recipient's kidney disease on the potential donor's life, the expected financial and social impact if the intended recipient receives a transplant, or the anticipated financial and social burdens if the intended recipient does not receive a transplant. Transplant social workers and living donor advocates are well positioned to engage potential donors in a more extensive, structured dialogue about their motivations for donating.

Enhance risk communication

Transplant centers should apply findings from behavioral and decision sciences research to improve the presentation of risk information. Experimentation on the impact of different methods of framing and presenting risks on donor comprehension is essential to improve the informed consent process. Studies report that willingness to consider living kidney donation is higher when the risks are described in terms of gain (survival rates) instead of loss (death rates) (44,45), but the impact of these framing effects on potential donors' ability to recall and process the risks has not been assessed. Use of visual diagrams to express risk could enhance accurate risk perception by countering the tendency to overestimate the risk of high-magnitude, low-probability events (46,47), such as the risk of ESRD post-donor nephrectomy. Clear risk communication is even more important if a donor wishes to accept increased marginal risks.

Understand donor risk acceptance

Little is known about the quantitative level of risk that potential donors will tolerate. Young et al (29) reported that 28% of individuals who were not yet being evaluated as donors were willing to accept a 0% risk of developing ESRD, 35% accepted a 0.1% risk and 38% accepted a >0.3% risk. However, these data were obtained at a single time point without an explanation of why the respondent found a particular risk level acceptable. Future research should assess: (1) Does this level of acceptable risk change over the course of the evaluation and donation process? (2) How do donors weigh the medical risks of donation against any perceived benefits of donation or perceived risks of not donating? and (3) What motivates some potential donors to accept higher risks than other potential donors? Answers to these questions will help transplant centers evaluate the impact of the donor education and informed consent processes on donors' risk comprehension, and to interpret a potential donor's risk acceptance in the larger context of their values and preferences. The stability of risk acceptance is crucial to determining the timing and frequency of shared decision-making discussions for potential donors. For example, evidence that donors accept higher risks at the beginning of the evaluation and lower risks just before donation could affect how a discretionary donor's risk tolerances are interpreted and integrated into the process of shared decision-making about their donor status.

Assess transplant center practices

Research should assess how transplant centers currently evaluate risks to medically complex donors, and what under what circumstances, if any, each center permits medically complex individuals to donate. Centers that accept a higher number of medically complex donors should be asked to share how they engage donors in discussions about their increased risks. Analysis of the short-term outcomes among these centers would illuminate whether medically complex donors have a higher rate of perioperative complications or mortality. In addition, centers with formal processes for discretionary donors to appeal determinations that they are not eligible to donate could be asked to share the advantages and disadvantages of their system. These centers will be critical in creating the basis for best practice guidelines for donor appeals.

Conclusion

As patient-centered and personalized approaches are being embraced in the practice of medicine, the development of more donor-centered approaches to living kidney donor evaluation are necessary. Shifting to a donor-centered model will require a better understanding of individual risk thresholds, donors' tolerance for risk, and how these are balanced with the motivations for donating. Transplant centers must communicate risk information and risk thresholds in ways that are easily understandable. In addition, potential donors should be empowered to engage in a joint decision-making process with the transplant team.

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