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To tell or not to tell: attitudes of transplant surgeons and transplant nephrologists regarding the disclosure of recipient information to living kidney donors

Meadow J, Thistlethwaite JR Jr., Rodrigue JR, Mandelbrot DA, Ross LF. To tell or not to tell: attitudes of transplant surgeons and transplant nephrologists regarding the disclosure of recipient information to living kidney donors.

Abstract: Background: Organ Procurement and Transplantation Network policy regarding “Living Donation Informed Consent Requirements” only requires general disclosure of candidate health information to prospective living kidney donors. We examined attitudes of transplant surgeons and transplant nephrologists regarding greater disclosure.

Methods: Web-based and mailed surveys to explore attitudes about disclosing potential recipient health information, health-associated behaviors, and lifestyle choices to living donors.

Results: Of 397 potential participants, 111 eligible participants (28%) fully or partially responded. Respondents were split between surgeons (42%) and nephrologists (58%). While 72% believed that general disclosure did not require explicit permission, 88% believed that disclosure of specific recipient information did. Many would disclose more information if legally permissible. Over 65% thought disclosure of recipient information should not depend on the donor–recipient relationship. Virtually all supported disclosing expected one- and five-yr graft survival and anticipated deceased donor wait-time. Sixty-six percent supported disclosing non-compliance or difficulty taking medications. Support was divided for disclosure of HIV (52%), hepatitis (49%), smoking (53%), illicit drugs (50%), alcohol (49%), and psychiatric history (44%).

Conclusions: While virtually all respondents support disclosing recipient information directly relevant to graft and patient survival to prospective living donors, they are divided about sharing other recipient health, health behavior, and/or lifestyle information.

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Key words: disclosure – kidney transplantation – living donors – physician attitudes – privacy – transplant recipient

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Rules about privacy and confidentiality in the medical setting assume a traditional doctor–patient relationship of a single doctor treating a single

patient. Living donor kidney transplantation, however, involves two patients. Because each patient’s decision to participate in a living donor kidney

transplant is affected by the other's actions and prior actions, living donor kidney transplantation creates the potential for tension between one participant's desire for confidentiality and the other's desire for information to make an informed decision. Currently, it is not required to provide living organ donors with any information regarding the health or risk behaviors of their intended recipients. Rather, Organ Procurement and Transplantation Network (OPTN) policy regarding "Living Donation Informed Consent Requirements" states that the donor must be informed that "[A]ny transplant candidate may have risk factors for increased morbidity or mortality that are not disclosed to the donor" (1). That is, living donors are entitled to a general warning regarding the possibility that any recipient may have health-related problems that limit graft or patient survival, but specific information about their potential recipient does not need to be provided.

Prospective living donors may want to know health information and health behaviors of potential recipients to decide whether or not to accept the risks of donation (from peri-operative risks including death to long-term risks of end-stage renal disease and cardiovascular disease) (2–5). Donors may want to know about the health status and life expectancy of the candidate with and without a living donor transplant as well as the likely wait-time for a deceased donor graft to decide whether the benefits of donation sufficiently outweigh the risks from their own perspective (6–8). For example, for some donors, knowing whether the intended transplant is a re-transplant that is needed because of recipient medication non-adherence may be integral to their decision-making process (6). Disclosure of other candidate health habits like smoking, drugs, and alcohol use is more controversial because there are survey data that show willingness to give lower priority to candidates who exhibit these behaviors for deceased donor organs by both professionals and the public (9–11), even if they have no impact on patient or graft survival. There is therefore a tension between the donor's desire for information and the recipient's desire for privacy. While this tension may be less emotionally charged in Good Samaritan (non-directed) donations where the recipient does not have a relationship with the donor, it may present complicated practical issues for family members who may not wish to reveal certain aspects of their lifestyle (like men having sex with men or intravenous drug use) to their relatives. However, family members are also more likely to know each other's lifestyle information, and thus, explicit disclosure of such information may not even be necessary.

Although the OPTN policy only requires donors to be privy to general information, little is known about how transplant teams actually handle health and health behavior information sharing, and what their opinions are on how it should be handled (12). We administered a survey to two groups of physician stakeholders involved in kidney transplantation – transplant surgeons and transplant nephrologists – asking about their current practices with regard to disclosing recipient health and health behavior information to potential living kidney donors. Specifically, we were interested in exploring whether transplant surgeons and transplant nephrologists would have the same attitudes about disclosing health, health behavior, and lifestyle information about transplant recipients to living donors, and whether their attitudes would change (i) depending upon the relationship between the donor and recipient, and (ii) if they were not constrained by strict privacy laws.

Materials and methods

We created a list of kidney transplant surgeons and transplant nephrologists residing in the United States from the American Society of Transplantation (AST) and American Society of Transplant Surgeons (ASTS) online directories as well as from institutional websites. Using the AST online directory, we limited our search to physician members of three specialty membership categories: adult nephrology, surgery-renal, and surgery-transplant at US centers. Using the ASTS online directory, we limited our search to physicians (MD, MBBS, DO) and excluded those who were fellows, lived outside the United States, and/or self-identified as thoracic transplant surgeons. We used institutional websites for additional email addresses. Duplicates were deleted. We used a random number generator to split the list into three sections for three concurrent studies using the same participant population, which resulted in 459 potential participants being contacted for this study. Potential participants were excluded if they responded to the survey requesting to be excluded, lacked a valid e-mail, had been incorrectly labeled a transplant surgeon or transplant nephrologist, or had previously opted out of surveys from surveymonkey.com.

The survey (see Appendix S1) included questions grouped into eight categories to ascertain current practices of transplant surgeons and transplant nephrologists (hereinafter referred to as transplant professionals) and their opinions regarding disclosure of kidney transplant recipient health and health behavior information to a potential living donor. We asked respondents what information

(general or specific) they currently disclose to donors about recipients given Health Insurance Portability and Accountability Act (HIPAA) legislation and what information they would disclose in the setting in which HIPAA and other strict privacy laws were not in place. Questions about disclosure of specific health conditions, health behaviors, and lifestyle were adapted from a previous study by Rodrigue et al. (6). The final survey went through several iterations by the authors to ensure consistent interpretability by different professional stakeholders. For statistical purposes, disclosure questions with 4-point Likert scales (Strongly Support, Moderately Support, Moderately Oppose, Strongly Oppose) were grouped into “Support” and “Oppose.” We collected demographic information on professional role, age, gender, and center characteristics. Respondent age was collected in five-yr age groups to promote confidentiality. For comparison purposes, age responses were grouped into “less than or equal to 50 yr old” vs. “greater than 50 yr old.” Data were analyzed using SPSS v. 22 (SPSS Inc., Chicago, IL, USA). Comparison of proportions between nephrologists and surgeons was performed using chi-squared tests. Test statistics and degrees of freedom are reported along with p values. Fisher’s exact test was used as needed due to small cell counts. McNemar–Bowker tests were performed to compare individual participants’ responses to paired questions.

Potential respondents were contacted a maximum of four times between July and August 2013.

Three contacts were by email and one by United States mail. Survey responses were included if received before December 1, 2013. This study was approved by the University of Chicago Institutional Review Board, and written consent was waived before administering the survey to any participants.

Results

We contacted 459 potential respondents, 62 of whom were subsequently excluded (19 self-excluded and 43 for failing to meet inclusion criteria). Of the remaining 397 potential respondents, 119 either fully or partially responded. Eight were excluded from further analysis because the respondent was neither a transplant surgeon nor a transplant nephrologist, resulting in a final total of 111 valid surveys (28%) for analysis.

Demographics are shown in Table 1. Eighty-three percent (91/109) were male, and 58% (64/111) were transplant nephrologists. There was no difference in age or gender between nephrologists and surgeons. There was also no difference between responders and non-responders based on gender (91/109 or 83% of responders were male vs. 221/278 or 79% of non-responders, $\chi^2_{(1)} = 0.798$, $p = 0.372$) or professional role (64/111 or 58% of responders were transplant nephrologists vs. 146/278 or 53% of non-responders, $\chi^2_{(1)} = 0.844$, $p = 0.358$). Eighty-six responded by the web (77%). There were no demographic differences

Table 1. Respondent demographics

Demographics (N = 111)	Total N = 111 n (%)	Transplant surgeon N = 47 n (%)	Transplant nephrologist N = 64 N (%)
Specialty			
Transplant surgeon	47 (42)	47 (100)	0 (0)
Nephrologist	64 (58)	0 (0)	64 (100) _b
Age (N = 110) ^a			
<41	32 (29)	15 (32)	17 (27)
41–50	20 (18)	10 (21)	10 (16)
51–60	36 (33)	14 (30)	22 (35)
61+	22 (20)	8 (17) _c	14 (22) _b
Gender (N = 109) ^a			
Male	91 (83)	39 (85)	52 (82)
Female	18 (17)	7 (15)	11 (18) _d
Approximate number of living donor kidney transplants done at your center yearly? (N = 109) ^a			
Range [25%–75%]; median	[14–60]; 30	[15–70]; 35	[12–60]; 28 _d
Approximate number of deceased donor kidney transplants done at your center yearly? (N = 109) ^a			
Range [25%–75%]; median	25–100; 40	26–100; 40	25–100; 48

^aN varies due to partial non-responders.

^b63 transplant nephrologists.

^c46 transplant surgeons.

^d62 transplant nephrologists.

between those who responded online vs. by mail (data not shown).

There was strong support that specific recipient information was private and should not be disclosed without the explicit consent of the recipient. In contrast, transplant professionals felt that general information did not require explicit permission to be disclosed. While 30 of 107 respondents (28%) thought disclosure of general information to living donors should require explicit recipient permission, 97 of 110 (88%) thought disclosure of specific information should require explicit permission. Likewise, while 67% (74/110) thought a recipient should be allowed to decline to have specific information that may impact on graft or patient survival to be shared with their donor, only 31% (33/107) of respondents thought a recipient should be allowed to decline to have general information shared. That is, two-thirds supported the recipient’s right to decline to share

specific information, but less than one-third supported this right with respect to general information. There were no differences in attitudes based on specialty (see Table 2). There were also no differences based on gender and age (data not shown).

Over 65% of physicians stated that the standard of disclosure of recipient information should not depend on the relationship between the recipient and the donor. As the relationship grew less intimate, more respondents believed that the donor was entitled to less information than what should be told to a first-degree relative or spouse, although up to 3% of physicians thought that the transplant team should give more information to a friend, extended family member, chain donor, or altruistic stranger than the team would give to a first-degree relative or spouse. There were no differences in attitudes between transplant surgeons and transplant nephrologists (see Table 3). There

Table 2. Transplant professionals’ attitudes regarding recipient control of disclosure to living donors

	Should disclosure to living donors require explicit recipient permission? n/d ^a (%)		Should a recipient be allowed to decline to share with their donor medical information that may impact on graft or patient survival? n/d ^a (%)	
	For patient specific info (A)	Only in general terms (B)	For patient specific info (C)	Only in general terms (D)
Transplant Surgeons responding “Yes”	39/46 (85)	17/45 (38)	27/46 (59)	16/45 (36)
Transplant Nephrologists responding “Yes”	58/64 (91)	13/62 (21)	47/64 (73)	17/62 (27)

χ^2 comparisons between surgeons and nephrologists were statistically insignificant for all comparisons (Column A $\chi^2_{(1)} = 0.877$ $p = 0.349$, Column B $\chi^2_{(1)} = 3.652$ $p = 0.056$, Column C $\chi^2_{(1)} = 2.642$ $p = 0.104$, Column D $\chi^2_{(1)} = 0.809$ $p = 0.368$).
^an/d = numerator/denominator.

Table 3. Pre-donation should the transplant team use the same disclosure policies and practices if the living donor is not a first-degree relative or spouse, but instead is...

	Surgeon N = 46 nephrologist N = 64	Less information n (%)	Same amount of information n (%)	More information n (%)
Total N = 110				
Extended Family	Surgeon	5 (11)	40 (87)	1 (2)
	Nephrologist	7 (11)	55 (86)	2 (3)
Friend	Surgeon	7 (15)	38 (83)	1 (2)
	Nephrologist	10 (16)	52 (81)	2 (3)
Affiliation	Surgeon	9 (20)	36 (78)	1 (2)
	Nephrologist	14 (22)	48 (75)	2 (3)
Chain	Surgeon	14 (30)	32 (70)	0 (0)
	Nephrologist	21 (33)	41 (64)	2 (3)
Altruistic stranger ^a	Surgeon ^b	15 (33)	30 (67)	0 (0)
	Nephrologist ^c	21 (33)	42 (66)	1 (2)

Fisher’s exact tests were not statistically significant for any comparison between surgeons and nephrologists (Extended Family $p = 1.00$, Friend $p = 1.00$, Affiliation $p = 0.920$, Chain $p = 0.652$, Altruistic stranger $p = 1.00$).

^aN = 109.

^bN = 45.

^cPercentages do not add up to 100 due to rounding.

were also no differences in attitudes based on gender or age (data not shown).

Fig. 1A shows respondents' current disclosure practice and what respondents would disclose if HIPAA and other privacy laws were not in place for transplant surgeons and transplant nephrologists combined. Results showed that overall, if HIPAA were not in place transplant professionals would be inclined to share more information, but that the main shift was from disclosing general information to disclosing specific information rather than from non-disclosure to disclosure. That is, while most respondents who did not share any information currently would continue not to share information in the hypothetical situation, our data clearly show a move by respondents from disclosure of general information to specific information. This same pattern holds for each question and is statistically significant (McNemar–Bowker₍₃₎ > 13, $p < 0.004$ for each as delineated in the legend of Fig. 1A).

Fig. 1B examines current disclosure practices of transplant surgeons and transplant nephrologists. Current disclosure practices were the same for five of the six factors. The only difference between the two physician groups is the distribution of current disclosure of psychosocial information that impacts graft survival. While both surgeons and nephrologists were most likely to disclose general information (46% [21/46] of surgeons and 58% [37/64] of nephrologists), surgeons were more likely to disclose specific information (28% [13/46]) than nephrologists (9% [6/64]) and less likely to disclose no psychosocial information (26% [12/46] vs. 33% [21/64], respectively), ($\chi^2_{(2)} = 6.681$, $p = 0.035$). There were no differences in current disclosure practices based on gender or age for any of the six factors (data not shown).

Fig. 1C examines disclosure practices of transplant surgeons and transplant nephrologists if strict privacy laws were not in place. There were no differences between surgeons and nephrologists ($\chi^2_{(2)} < 4.628$, $p > 0.099$ for each comparison as delineated in the legend of Fig. 1C). There were also no differences based on gender or age (data not shown).

Fig. 2 depicts the extent to which respondents support the concept that a transplant team share particular recipient information with the donor pre-donation in the setting of a donation to a close family member divided by specialty. The overall level of support for disclosure of all pieces of information was relatively high, with the lowest level coming at 44% (psychiatric history). For information that could affect graft and patient survival (e.g., survival at one yr, survival at five yr, how

long the potential recipient would have to wait for a deceased donor organ), support for disclosure was almost unanimous. For information about health conditions that do not have a direct causal relationship with recipient and graft survival (e.g., alcohol abuse and psychiatric history), support for disclosure was relatively evenly divided. Transplant surgeons were statistically more willing than transplant nephrologists to disclose recipient HIV/AIDS (31/46, 67% vs. 26/64, 41%, $\chi^2_{(1)} = 7.680$, $p = 0.006$). Otherwise, there were no differences by specialty. There were also no differences by age or gender (data not shown).

Discussion

Living kidney donor transplantation creates an exceptional case of the doctor–patient relationship in which there are multiple patients whose outcomes are interrelated. Potential recipients require health and health risk information about their donors because this information will impact graft survival and likelihood of disease transmission (13–15). Although all donors are tested for hepatitis and HIV infections prior to transplant, there is a small window in which false-negative testing results may occur in recently infected donors (13, 16). Although donors are not affected directly by recipient health and health behaviors, recipient health information impacts graft and patient survival, information that may influence the donor's decision to donate. We found that both transplant surgeons and transplant nephrologists have similar attitudes about disclosing information to donors. In general, both wanted to disclose health information that would impact graft and patient survival, but did not support disclosure of other health behavior and lifestyle information.

Two consensus panels have addressed disclosure of recipient information to prospective donors. In 2000, the Live Donor Consensus Group was convened by the National Kidney Foundation, the American Societies of Transplantation, Transplant Surgeons, and Nephrology. The Consensus Group proposed a list of elements of disclosure for potential living donors. It included both information regarding specific risks and benefits to the potential recipient and expected outcome of transplantation for the recipient (17). It did not state whether recipient permission was needed. In 2004, the Ethics Committee of The Transplantation Society (TTS) published a statement on ethical considerations pertaining to the live kidney donor (18). In that document, disclosure was not addressed, but it

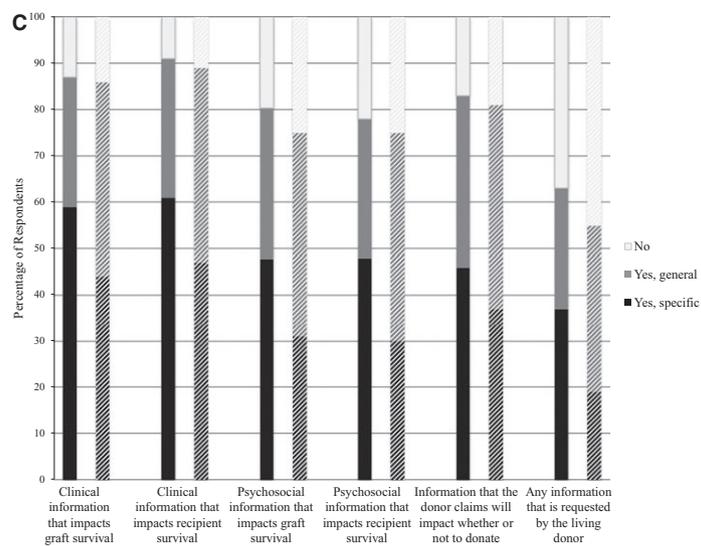
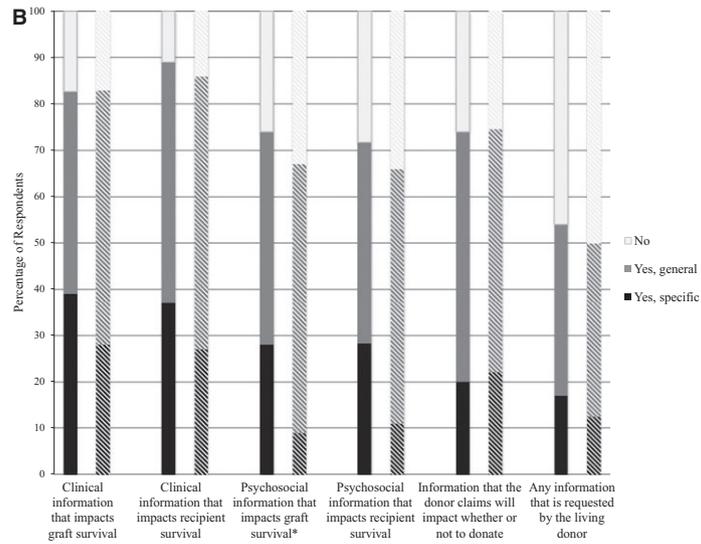
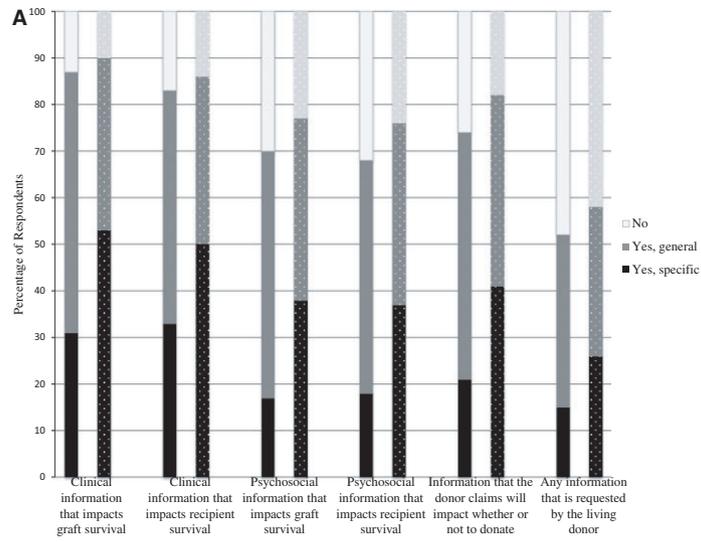


Fig. 1. (A) Do you currently share the following recipient information with a potential living donor pre-donation? (What would you do without HIPAA regulations?). Solid: Current Practice. Spotted: Hypothetical Practice Without HIPAA regulations. Black: Yes, specific information; Gray: Yes, general; White: No. McNemar–Bowker comparisons of Current Practice vs. Without HIPAA were statistically significant for each question (Clinical information that impacts graft survival, McNemar–Bowker₍₃₎ = 26 000 p < 0.001; Clinical information that impacts recipient survival, McNemar–Bowker₍₃₎ = 22 000 p < 0.001; Psychosocial information that impacts graft survival, McNemar–Bowker₍₃₎ = 26 000 p < 0.001; Psychosocial information that impacts recipient survival, McNemar–Bowker₍₃₎ = 24 000, p < 0.001; Information that the donor claims will impact whether or not to donate, McNemar–Bowker₍₃₎ = 22 800 p < 0.001; Any information that is requested by the living donor, McNemar–Bowker₍₃₎ = 13 400, p = 0.004). (B) Do you currently share the following recipient information with a potential living donor pre-donation? Transplant Surgeons vs. Transplant Nephrologists. Solid: Transplant Surgeons. Striped: Transplant Nephrologists. Black: Yes, specific information; Gray: Yes, general; White: No. *Transplant Surgeons currently share more psychosocial information that impacts graft survival, $\chi^2_{(2)} = 6681, p = 0.035$. (C) If HIPAA and other privacy restrictions were not in place, what information would you/your transplant team share with a potential living donor pre-donation? Transplant Surgeons vs. Transplant Nephrologists. Solid: Transplant Surgeons. Striped: Transplant Nephrologists. Black: Yes, specific information; Gray: Yes, general; White: No. $\chi^2_{(2)}$ comparisons were not statistically significant for any comparison between surgeons and nephrologists (Clinical information that impacts graft survival, $\chi^2_{(2)} = 2120 p = 0.346$; Clinical information that impacts recipient survival, $\chi^2_{(2)} = 2644 p = 0.267$; Psychosocial information that impacts graft survival, $\chi^2_{(2)} = 3124 p = 0.210$; Psychosocial information that impacts recipient survival, $\chi^2_{(2)} = 3998 p = 0.135$; Information that the donor claims will impact whether or not to donate, $\chi^2_{(2)} = 0.764 p = 0.683$; Any information that is requested by the living donor, $\chi^2_{(2)} = 4628 p = 0.099$).

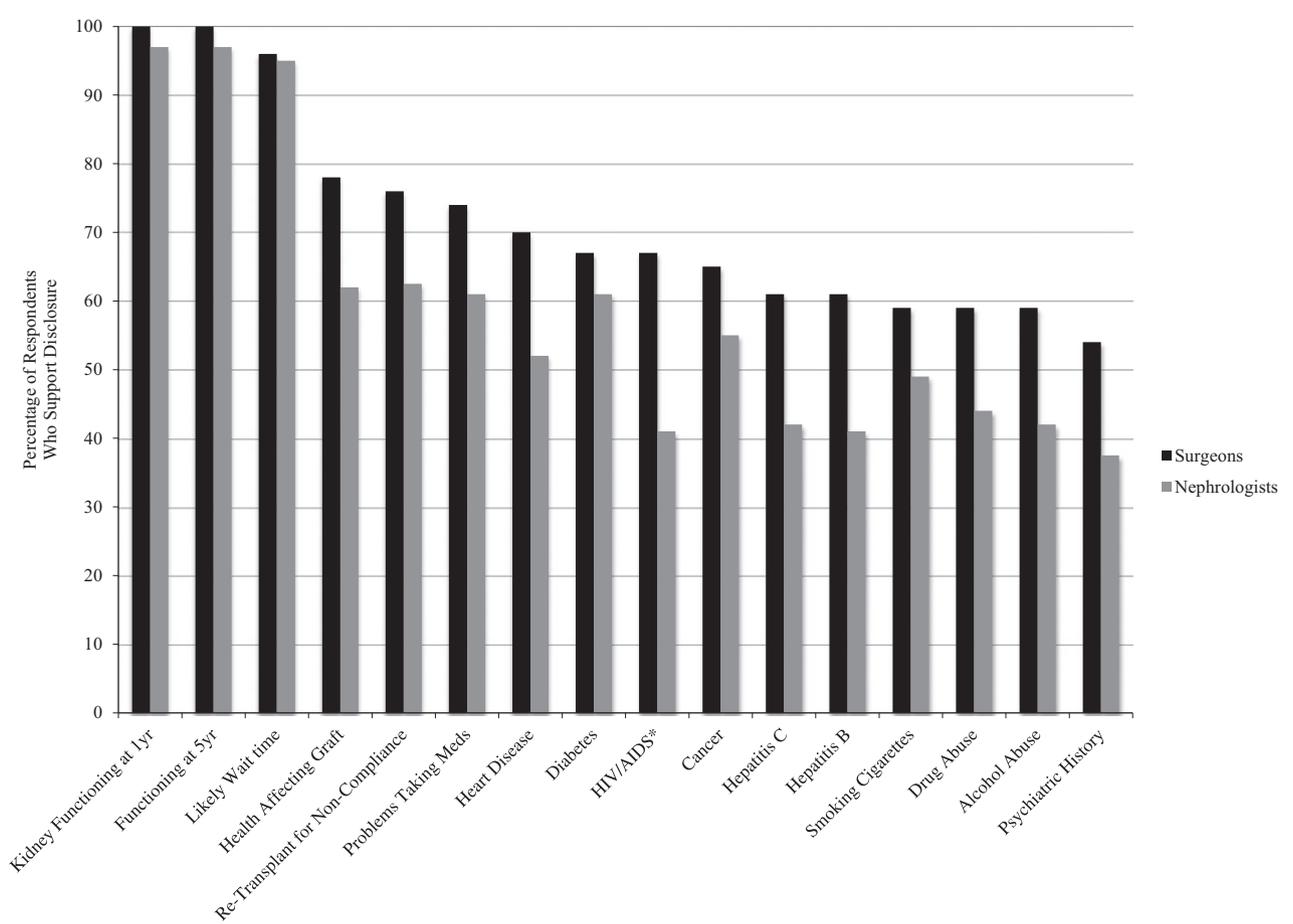


Fig. 2. To what extent do you support the concept that a transplant team share this recipient information with the donor pre-donation? Black: Transplant Surgeons. Gray: Transplant Nephrologists. *Transplant surgeons were more supportive of disclosing HIV than transplant nephrologists, $\chi^2_{(1)} = 7680, p = 0.006$.

was addressed in 2005 in a follow-up ethics statement “of the Vancouver Forum on the Live Lung, Liver, Pancreas, and Intestine Donor.” The Ethics Committee affirmed that:

“Informed consent is predicated upon the individual’s receipt of adequate information about the evaluation process to become an organ donor and the donation procedure and possible

consequences. . . In addition, the potential donor should be given information about:

1. Any specific recipient conditions which may impact upon the decision to donate; however, no information can be given to the potential donor until permission is obtained from the recipient;
2. Expected transplant outcomes (favorable and un-favorable) for the recipient (19 at 1387)."

Both consensus panels supported disclosure of relevant recipient health information and health behaviors to donors, although the TTS Ethics Committee believed that the donor should only be given specific information with permission from the recipient. Our data reflect the position of the TTS Ethics Committee. The majority of transplant professionals support the idea that donors should have access to medically relevant information about their intended recipient, although the majority supports explicit recipient consent for the disclosure of specific information. However, if strict privacy laws were not in place; that is, if recipient consent were not required, the number of physicians disclosing any information would rise, with a particular increase in the number of physicians willing to disclose specific information as compared to general information.

Although transplant professionals support the sharing of information, a minority differentiate which donors should receive what information, with greater support for sharing information with family members and less support for sharing recipient information with altruistic strangers, chain, and exchange donors (20). As intimacy between donor and recipient decreased, there was a slight decreased willingness to share information. This may be due to personal beliefs about the sharing of health information within families vs. the sharing of health information beyond the family (21). Empirical data about disclosure in the literature often focus on intrafamilial sharing of genetic information. The studies show that disclosures within families are not homogeneous and may depend not solely on biological relatedness, but rather on a variety of psychosocial and emotional factors as well as the quality of the relationship (22–24). This suggests that there may need to be some negotiation regarding content of disclosure with donor–recipient pairs.

Transplant surgeons and transplant nephrologists also differentiate what information should be disclosed. There is more support for disclosure of health information that has direct impact on recipient and graft survival and less support for

disclosure of health information that has less direct impact. This is also true for other stakeholder groups such as potential and past living donors and potential and past transplant recipients (6, 7).

There are at least two arguments why some may question the ethics of disclosing recipient information to donors. First, some may argue that it is unfair to require a candidate to waive his right to privacy in order to be eligible for a living kidney graft (8). Privacy is maintained in the case of deceased donor kidney transplantation where the kidney, once donated, is viewed as a public good and the deceased donor's family is not involved in recipient selection and is only given minimal information about the recipient. They must trust that the transplant community has assessed the candidate to be an appropriate transplant recipient. But living donor organs are considered a private good over which the donor has greater authority in its allocation, and this decision may be based on whether the donor believes that the recipient will be a good steward (9).

Second, some may question whether the living donor should be privy to recipient health information and recipient behaviors impacting health on the grounds that the donor may decide not to donate based on discriminatory or stigmatizing attitudes about specific behaviors and/or lifestyles. Although Formica et al. in an article about disclosing recipient HIV status conceded that: "It is not for the medical community to judge the reasons why they may choose not to donate" (8 at p. 926), Formica et al. (8) concluded that recipient privacy trumps the donor's right to know. Their conclusion is based on the utilitarian justification that candidacy approval by a transplant team means that the candidate's expected outcomes were judged "good enough." The counterargument is that while the medical team's judgment should only focus on clinically relevant factors, living donors do not have this obligation and should not be held to the same standards as transplant professionals. Rather, living donors should have the freedom to determine what factors to weigh in deciding whether or not the benefits of their donation outweigh the risks, and these factors need not be the same as the ones used by healthcare providers. Data show that potential donors (and the public at large) may believe that non-clinically relevant factors are relevant to donation decisions (6, 7). Leaving out specific health information because it may be stigmatizing fails to respect the autonomy of the donors to make an informed decision based on their own values (12).

The main limitation to this survey was the low response rate of 28%. Survey response rate has been declining over the past 20 yr regardless of mode of administration (postal surveys, phone surveys, and email surveys) (25, 26). Nevertheless, McLeod et al. found that less than one-third of large national surveys (administered mainly by postal mail with an incentive) published between 2000 and 2010 had a response rate of <40% (27). In contrast, in 2000, Cook et al. found that the mean response to electronic surveys was only 39.6% (standard deviation 19.6%) (26). Even small incentives have been shown to improve the response rate (27–29). Despite a limited budget that precluded us from offering an incentive, we attempted to improve the response rate using mixed methods (three electronic requests and one postal request), which has been shown to help (27, 28). The concern of a low response rate is that responders may differ from non-responders, leading to biased results. This concern is slightly minimized in our data as there were no statistical differences between responders and non-responders on the basis of gender or specialty. This is consistent with “previous reviews [that] identified smaller-than-anticipated differences between physician respondents and non-responders and between early and late responders, suggesting low rates of nonresponse bias.” (28 at p. 315). VanGeest et al. explain that the lack of non-response bias is due to “the homogeneity of physicians with regard to knowledge, training, attitudes, and behavior (references omitted).” (28 at p. 315).

A second limitation is that while transplant surgeons and transplant nephrologists represent two different physician stakeholder groups, there are many other healthcare professional stakeholder groups including nurses, transplant social workers, donor advocates, and the like. Surprisingly, there is not much research on attitudinal differences between nephrologists and surgeons (30). Rather, most studies focus on variability between renal transplant programs and offered little insight into similarities and differences between surgeon respondents and nephrologist respondents (12, 31, 32). We found that surgeons and nephrologists had strikingly similar views. Still, additional research is needed to determine whether other professionals have similar attitudes about disclosure and these perspectives must be studied along with the attitudes and perspectives of donors, recipients, families, and other invested stakeholders.

In summary, our study affirms the recommendations of two consensus panels of leaders in the transplant community regarding disclosure of relevant recipient health information to prospective

living donors. The majority of our respondents support the disclosure of recipient information that is relevant to graft and patient survival. Transplant professionals are divided about sharing other recipient health information and health behaviors. Current OPTN policy requires only minimal disclosure, but permits broader sharing if consent is obtained. More data are needed to determine actual disclosure and consent practices. We offer ethical arguments and empirical data from two stakeholder groups that support greater disclosure. Other stakeholders should be surveyed, especially public stakeholders whose privacy regarding health, health behavior, and lifestyle information would be at stake.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Survey, Disclosures to living donors.