

Disclosing Health and Health Behavior Information between Living Donors and Their Recipients

Leslie Mataya, Jacqueline Meadow, [...], and Lainie Friedman Ross

Abstract

Background and objectives

Living donor guidelines—both national and international—either do not address or are vague about what information can be shared between prospective living donors and transplant candidates, as well as when to make such disclosures and who should make them. This study explored the attitudes of donors and recipients regarding how much information they believe should be shared.

Design, setting, participants, & measurements

Two Email invitations were sent by the National Kidney Foundation (national headquarters) to its Email listservs, inviting members to participate in an online survey to assess the attitudes of kidney transplant stakeholders regarding the disclosure of health and health risk behavior information.

Results

From approximately 4200 unique Email addresses, 392 (9.3%) respondents completed part or all of the survey. The analyses were limited to the 236 respondents who self-identified as either donors (potential and actual, $n=160$) or recipients (candidates and actual, $n=76$). Overall, 79% (186 of 234) of respondents supported disclosure of general recipient health information that would affect post-transplant outcome to donors, and 88% (207 of 235) supported disclosure of general donor health information to recipients. Recipients and donors were also supportive of sharing donor and recipient information, particularly information relevant to graft and patient survival. There is some reticence, however, about sharing social information. The closer the relationship, the more information they are willing to share. Both donors and recipients wanted the transplant team involved in the information disclosure. Over three quarters of donors (79%) and recipients (78%) did not think the recipient had a right to know why a donor was excluded from donating.

Conclusions

Both donors and recipients want a significant amount of health information to be disclosed. The opinions of other stakeholders need to be surveyed to determine whether a revision of current policies and practices is warranted.

Keywords: kidney transplantation, risk factors, living donors, disclosure, privacy

Introduction

Living donor guidelines—both national and international—either do not address or are vague about what information can be shared between prospective living donors and transplant candidates, as well as when to make such disclosures and who should make them (1–5). Information about the donor may be of significant interest to the recipient to decide whether to accept the organ. Likewise, a potential donor may want information about an intended recipient to decide whether to offer the organ. How much information should be shared with each party and by whom are controversial questions.

Potential living donors undergo extensive screening both to try to ensure that they are physically, psychologically, and socially healthy enough to safely undergo unilateral nephrectomy and to identify their risk of transmitting certain infectious diseases or cancers. In some cases, donors may be excluded because of the disease transmission risk they pose to their recipient candidates. Although potential donors are usually provided with specific information about why they are excluded, recipients are only told that the potential donor was excluded.

Some potential donors may participate in high-risk activities that expose them to the risk of being infected with HIV, hepatitis B, or hepatitis C, even if they are negative at screening. Transplant professionals want to identify these donors because these infections can be transmitted in the graft (6). For deceased donor organs, the United Network for Organ Sharing (UNOS)/Organ Procurement and Transplantation Network (OPTN) has a policy that requires that candidates be informed whether their deceased donor meets the Centers for Disease Control and Prevention increased risk classification for infection transmission (15.3 bullet 2), even if the donor tests negative (7). Whether this classification must be disclosed for living donors is not clearly articulated. What the policy handbook states is that recipients should be told that living donors are required to undergo screening for a list of transmissible diseases (15.3.2) but that “there is no comprehensive way to screen potential deceased and living donors for all transmissible diseases” (15.3.3) (7).

Recipient candidate health, by contrast, does not pose any medical risk to the donor and therefore UNOS/OPTN guidance is to not share any health information. Rather, the transplant team is instructed to tell living donors that “any transplant candidate might have risk factors for increased morbidity or mortality that are not disclosed to the potential donor” (Table 14.1) (7). Given that donors expose themselves to the short- and long-term risks of unilateral nephrectomy, some believe that donors should have access to recipient health and health risk behavior information that may affect their decision on whether the benefit of donation outweighs these risks (5).

We designed a survey to assess the attitudes of living kidney transplant stakeholders regarding the disclosure of health information and information about social behaviors related to health. We had four hypotheses: First, both donors and recipients would want more information shared than currently is required to be shared. Second, the closer donors and recipients are emotionally, the more willing they would be to share information. Third, both donors and recipients would want the transplant team involved in the sharing of this information. Fourth, donors would believe that recipients do not have a right to know why a donor was excluded, but recipients would believe that they do.

Materials and Methods

With permission and help from the National Kidney Foundation (NKF) (national office), two invitations (July and August 2013) were sent to NKF-maintained listservs (approximately 2500 transAction Council members; approximately 1500 living donation members, which includes some family and professionals; and approximately 200 living donor advocate professionals), inviting them to participate in an online survey ([Supplemental Appendix](#)). Individuals aged <18 years were excluded.

The survey focused on attitudes regarding disclosure of information between living donors and recipients: what general information should be given, what specific information should be given, and who should be involved in the disclosure process. The content was developed based on a study by Rodrigue *et al.* (8). Questions were asked about both scenarios: sharing donor information with the recipient and sharing recipient information with the donor. Respondents were also asked how information about donors and recipients should be obtained (*e.g.*, through friends, the Internet, etc.), whether a recipient had the right to know why a donor was excluded from donating, and how long a kidney should function after transplantation to make living donation worthwhile. Demographic questions included age, sex, race, ethnicity, and education level. Respondents were also asked to self-identify as a donor (prospective or actual), recipient (deceased donor recipients, living donor recipients, and candidates awaiting a transplant), health care provider (mainly living donor advocates), or other (which included family of donors and recipients, friends, individuals with kidney disease, and interested public). Of the donors, we asked them what their relationship is with their recipient, how well they know each other, and what personal information about themselves they have shared or intend to share with their recipient. Recipients were asked the same questions about their donor.

Statistical analysis was performed using SPSS software (version 21.0; SPSS Inc., Chicago, IL). Results were compared using chi-squared tests and *t* tests of independence. Approval from the University of Chicago Institutional Review Board was obtained and the requirement for written consent was waived. The research adheres to the requirements stipulated in the Declaration of Helsinki, and the clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the Declaration of Istanbul on Organ Trafficking and Transplant Tourism.

Results

Approximately 4200 Email addresses received two Emails from the NKF (national headquarters), inviting them to participate in an online survey. Of the 396 (9.4%) NKF stakeholders who opened the survey, 392 (9.3%) answered the age screening question, and 287 (6.9%) completed the demographics questions at the end of the survey. One hundred and sixty (56%) self-classified as donors, 76 (27%) as recipients, 13 (5%) as health care providers, and 13 (5%) as other. For the purpose of this article, we only focused on the 236 donors and recipients.

Of the 160 donor respondents, 146 (91%) had already donated and 14 (9%) were considering donating. Of the 76 recipient respondents, 44 (58%) received a living donor graft, 19 (25%) received a deceased donor graft, five (6.6%) had received both, five (6.6%) were waiting for a living donor graft, and three (4%) were on the deceased donor waitlist. [Table 1](#) provides additional demographics. Most respondents were aged ≤50 years, female, white, non-Hispanic, with some form of higher education (2-year degree or higher). Compared with recipients, donors were more likely to be aged <50 years (101 of 154 donors versus 27 of 76 recipients, $P<0.001$), non-Hispanic (153 of 154 versus 65 of 70, $P<0.02$), and female (127 of 158 donors versus 43 of 75 recipients, $P<0.001$).

Characteristic	Donors (n=160)	Recipients (n=76)
Age (years)		
<50	101 (63.1%)	27 (35.5%)
≥50	59 (36.9%)	49 (64.5%)
Sex		
Female	127 (79.4%)	43 (56.6%)
Male	33 (20.6%)	33 (43.4%)
Race		
White	153 (95.0%)	65 (85.7%)
Non-White	1 (0.6%)	5 (6.6%)
Education		
<2-year degree	10 (6.3%)	10 (13.2%)
≥2-year degree	150 (93.7%)	66 (86.8%)

Table 1.
Demographics

Overall, 79% (186 of 234) of respondents supported disclosure of general recipient health information that would affect recipient post-transplant outcome to donors, and 88% (207 of 235) of respondents supported disclosure of donor health information to recipients. Respondents also preferred

Our finding that both donors and recipients support greater sharing of health and health behavior information challenges the current approach to disclosure in organ transplantation. The current model of health care decision-making and information disclosure assumes an isolated autonomous individual who makes private health care decisions with his or her own physician (14,15). A number of bioethics scholars have argued that the focus on individual autonomy fails to fully capture moral agency, which is often inextricably intertwined in the family (16–19). A reevaluation of current policies should be considered, given that UNOS data reveal that over two thirds of living donor kidney transplants involve first-degree relatives, with a parent, child, sibling, or spouse as the donor (20). Interestingly, although our donor sample involves a high percentage of nondirected donors, they also support greater disclosure—giving further support for a reevaluation of current policies and practices.

Because most donors and recipients know each other well and their lives are intertwined, they may share health information and health-related behavior information with each other separate from their transplant interactions, and they may also choose to obtain information from other sources, again, not related to their transplant interactions. Our data suggest that many donors and recipients support such opportunities. Although our respondents showed reluctance in asking friends, spouses, and partners for information about prospective donors and recipients, approximately one half would browse the Internet to get additional information. Many preferred the participation of health care professionals when sharing information. It may behoove transplant programs to assess whether individual donor-recipient pairs want to share more information and if so, to offer to help facilitate this. In our current system, this would require permission and consensus of what is shared by the donor, the recipient, and the transplant team, with any party able to veto additional disclosure. Whether the presumption of strict privacy should be the norm needs further discussion and analysis.

There are four limitations of our results. First is the low response rate, which is typical for Internet surveys sent to a mailing list (21). Second, the survey offered discrete-choice responses to facilitate completion, but this may not capture the complexity and nuances of the respondents' attitudes. Third, respondents were at different stages in the donation and transplant process, and attitudes and disclosure practices may change with time and with changes in the legal and regulatory climate. Fourth, although the NKF listserv is a national listserv, its members self-select to join, and our respondents do not reflect the national demographics of living donors nor of individuals with ESRD. Rather, our respondents are more likely to self-identify as female or white and are more likely to have achieved higher educational status than is representative of the living donor and ESRD communities. Our sample was also not representative based on donor-recipient relationship. UNOS national data show that more than two thirds of donors and recipients are parents, siblings, children, or spouses. Our recipient respondents' demographics were aligned with national data; however, nondirected donors were heavily overrepresented in our sample (17% versus <2% in the national sample) (20). This may mean that the donors who responded to our survey do not know their intended recipient as well as a more typical donor. Because a closer relationship correlates with greater willingness to share information, our data may underestimate actual donor interest in sharing of information.

In living donor transplantation, most donors and recipients want a significant amount of health information to be disclosed. The closer the relationship, the more they are willing to share. There is some reticence, however, about sharing social information. Additional stakeholders need to be surveyed to understand the public's attitude toward the relative merits of privacy versus the right to know.

Disclosures

None.

Supplementary Material

Supplemental Data:

[Click here to view.](#)

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Footnotes

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