

Letter to the Editor

Miscommunicating NOTA Can Be Costly to Living Donors

To the Editor:

Misconceptions about whether and how living donors may receive financial support appear to be widespread. These misconceptions may be perpetuated by unclear or incomplete language in informed consent documents. Without accurate written information about the National Organ Transplant Act of 1984 (NOTA) (1), donors may forgo legal financial support and question their decision to donate. The financial burden of evaluation and donation (2) may disproportionately affect vulnerable populations. We recommend that the removal of financial disincentives begin by disclosing explicit and accurate information regarding available mechanisms to defray donors' costs.

We reviewed a convenience sample of informed consent forms for living donor (kidney $n = 8$, liver $n = 2$) and transplant candidate (kidney $n = 4$, liver $n = 2$) evaluation from nine geographically diverse centers with medium- and high-volume living donor programs. Our analysis focused on costs to donors that are clearly addressed by extant legislation and regulatory policy. We recognize that potential donors and recipients receive information from other sources, including conversations with the transplant team. However, the informed consent document may help ensure consistent donor education and is available for future reference should questions arise later.

We identified four misconceptions, which are reinforced by ambiguous language or omissions in donor informed consent documents (Table 1). Five of the six recipient consent forms did not include information about the financial implications for living donors.

Misconception 1: Donors can only be helped with the *medical costs of donation*.

Clarification: Donors may receive assistance to defray expenses of *travel, housing, food, childcare, and lost wages* during *evaluation, donation, and for 2 years post-surgery* (1,3,4).¹

¹The regulations that establish NLDAC only apply to federal grantees, they do not limit what is allowed by law under NOTA and its amendments (3). [Correction added after publication November 18, 2016: This footnote was added after initial publication.]

Misconception 2: Financial assistance can be provided to defray only a *donor's* expenses.

Clarification: Coverage may be offered for up to two *caregivers or family members* who help or accompany the donor (1,5).¹

Misconception 3: Donors may only be *reimbursed* for expenses.

Clarification: Others may pay the expenses *directly* on behalf of the donor (1).

Misconception 4: Only *National Living Donor Assistance Center (NLDAC)* is allowed to help donors.

Clarification: NOTA does not limit who can help donors.

Table 1 proposes revised language to address each misconception. In some cases, our proposals involve revision to the topics or language about living donor costs currently mandated by United Network for Organ Sharing (UNOS) for living donor evaluation consent (6). We suggest that similar language be integrated into recipient informed consent documents. Additionally, consent documents should include a link to an online, comprehensive list of organizations that offer donor financial assistance (e.g. the American Society of Transplantation's Living Kidney Donor Financial Toolkit (7)).

Conclusion

Failure to offer written, clear, and accurate information about available financial resources undermines informed decision making and the autonomy of donors and recipients. Although the transplant community agrees that financial disincentives should be eliminated, there is ongoing debate about the best way to achieve this goal (8–10). Until systemic changes are implemented, improving informed consent documents may ensure a more uniform experience for donor–recipient pairs and enhance their ability to take full advantage of existing mechanisms to reduce the financial burdens of living donation.

Table 1: Information about NOTA in living donor evaluation consent forms

Selected quote (italics added)	Issue	Suggestions for improvement	Proposed alternate wording
Misconception 1: Donors can only be helped with medical costs of donation.			
"The cost of outpatient prescriptions, childcare, travel, lost wages, and lodging <i>may not be covered.</i> " ¹	"May not" can erroneously be interpreted as indicating that it is not permitted.	Specify that it is legal to receive financial assistance to cover selected nonmedical expenses.	"It is illegal to make money from donation. Donors can get help to pay for donation costs. Allowed costs include (but are not limited to) travel, housing, lost wages, childcare, food, and medicine." ²
"You are only responsible for travel expenses and <i>expenses related to time off work</i> , unless your employer is able to provide paid time leave or allow the donor to use short-term disability."	Some consent forms note only the possibility of lost wages without mentioning that lost wages can be covered.	Specify that it is legal for donors to receive money to cover lost wages.	"You may need to take unpaid time off from work. It is legal for you to get financial help to cover your lost wages." ²
"...resources might be available to defray some <i>donation-related costs.</i> " ¹	Many consent forms only mention expenses of donation. Individuals who incur costs during evaluation but who are ultimately not eligible to donate may not know that they can receive financial assistance.	Discuss the permissibility of assistance for expenses related to evaluation and follow-up.	"There may be resources to pay for some costs of your evaluation or surgery. These resources may also help pay for your costs or lost wages for up to 2 years after you donate." ²
Misconception 2: Financial assistance can only be provided to defray a <i>donor's</i> expenses.			
" <i>Personal</i> expense of travel, housing, and lost wages related to live kidney donation might not be reimbursed."	Most consent forms only mention "personal" expenses for the donor.	State that allowable expenses for up to two donor caregivers or family may also be covered.	"Up to two people who help the donor (before, during, or after surgery) can get financial help. This help can pay for their travel, housing, lost wages, and childcare costs." ²
Misconception 3: Donors may only be <i>reimbursed</i> for expenses.			
"... you may have some of your expenses related to the donation procedure <i>reimbursed.</i> "	Many consent forms only use the term "reimbursed."	Clarify that donors do not need to pay out of pocket before receiving reimbursement.	"Others can help you pay for some of your donation expenses up front, with prepaid credit cards, or by reimbursement." ²
Misconception 4: Only <i>NLDAC</i> is allowed to help donors.			
"... <i>financial support</i> without profiting is allowed in order to offset potential costs that may be associated with donation..."	Many consent forms do not identify any specific sources of financial support.	Provide a link to a webpage with a comprehensive list of strategies for fund-raising and organizations that offer financial support for living donors.	"Many groups help cover the costs to living donors. Some donors and their recipients have set up ways to raise money to pay for the donor's expenses (e.g. bake sales, fund-raiser events, crowd-funding). Please refer to [AST Live Donor Financial Toolkit webpage] and talk to your social worker, financial counselor, and/or independent living donor advocate to get more information." ²
"Resources might be available to defray some donation-related costs (i.e. <i>The National Living Donor Assistance Center</i>)..."	Some centers only mention NLDAC, creating the impression that NLDAC is the only potential or legal source of support.		

¹UNOS Policy 14.3 "Informed Consent Requirements" requires that the following be disclosed to living donors: "Personal expenses of travel, housing, child care costs, and lost wages related to donation might not be reimbursed; however, resources might be available to defray some donation-related costs" (6).

²The regulations that establish NLDAC only apply to federal grantees, they do not limit what is allowed by law under NOTA and its amendments (3). [Correction added after publication November 18, 2016: Table footnote 2 was added after initial publication.]

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