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Elisa J. Gordon

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Introduction

Living Organ Donors' Stories: (Unmet) Expectations about Informed Consent, Outcomes, and Care

Elisa J. Gordon^{1*}, Symposium Editor

1) Feinberg School of Medicine, Northwestern University

* Correspondence concerning this article should be addressed to Elisa J. Gordon at the Institute for Healthcare Studies, Comprehensive Transplant Center, Feinberg School of Medicine, Northwestern University, 420 E. Superior St., 10th Floor, Chicago, IL 60611-3152.

Email: e-gordon@northwestern.edu

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Living donor organ transplantation has become standard treatment for patients with end-stage kidney or end-stage liver disease. Live donors comprised approximately 5,769 (34%) and 247 (4%) of all kidney and liver transplants in 2011, respectively (OPTN/UNOS). The reasons why people donate, the perception that donating does not entail a *decision* per se, and the attendant fears and anxieties living donors feel about donating, have all been previously well investigated (Lennerling, Forsberg, Meyer, & Nyberg, 2004; Papachristou, Walter, Frommer, & Klapp, 2010). But much less is known about how donors experienced the overall donation process including the donor evaluation, preparation, appreciation of risks, decision-making, informed consent, post-operative, recovery processes, and the impact of donating on all aspects of their life, from *their point of view*. Thus, a narrative approach is essential for gaining insights into these less well known phenomena.

There is good reason to remain concerned about the safety and ethical basis of living donation considering that living donors undergo serious health

risks for no direct medical benefit to themselves (Ethics Committee of the Transplantation Society, 2004; Laird, 2012; Neergaard, 2011; Ratner & Sandoval, 2010; Shelton, 2011). The situation raises serious ethical questions specifically about nonmaleficence and informed consent, and more broadly about using people as a means to an end. The absence of long-term information may not undermine a willing donor's commitment to save a loved one's life, but is certainly cause for concern among transplant clinicians who want to be sure to disclose information that may be material for donors in order to provide adequate informed consent. In other words, the disjuncture between what transplant clinicians find important to disclose to donors and what prospective donors need to know—which follows along the lines of what Elliot Mishler referred to as the 'voice of medicine' versus the 'voice of the lifeworld' (1984)—seems to complicate donors' preparation for donation. Donors' stories are important for addressing these concerns by identifying risks that typically do not get reported in the scientific literature—perhaps owing to a different

conceptualization of what should be construed as noteworthy risks—as well as by demonstrating how personal situations can enhance or detract from the experience overall.

This issue of *Narrative Inquiry in Bioethics* (NIB) affords a unique entrée into both the often heard and unheard stories of living organ donors. A set of topical areas were presented for the authors' consideration that relate to the donation process in general and the informed consent process more specifically: whether donors were prepared to donate; comprehended what they were told; could have understood the process better, as well as, the impact of donation on health, employment, finances, and personal relationships (Table 1). When soliciting donors' stories, every effort was made to include a full range of experiences—both good and bad—from a variety of donors: kidney donation, liver donation, adult-to-adult and adult-to-child

donation, related, unrelated, directed and anonymous (also known as 'altruistic' or 'good Samaritan' donors), paired chain exchange, and list exchange (Table 2)—in order to present a balanced perspective on live donation. Additionally, this issue includes a full breadth of stories about the donor experience, ranging from positive to mixed to negative (Table 3). While donors were given tremendous leeway in what stories they told, they were asked to focus their narratives on the lesser known dimensions of donation—the experience of it. While additional stories from liver donors would have helped to underscore common concerns among liver donors, we only received a few. Some of the donors are themselves health care professionals, active in the United Network for Organ Sharing (UNOS) or their local OPO, or have leveraged their experiences to help others by becoming a donor buddy or donor advocate. Given that we received more stories than

Table 1

Topical areas to address

What was the best part of donating?
 What was the worst part of donating?

Were you prepared for donation?
 Did you understand what clinicians told you about donating?
 Did your experiences match what you were told would happen?
 Would anything have helped you to understand the process better?

What was your relationship like with the recipient?
 How did your relationship affect your decision to donate?
 How did donation affect your relationship?

What made you decide to donate?
 Did you experience pressures to donate (pressures put on yourself self or by others)?

Donors undergo risks to life and health.
 How did you come to accept the risks to go ahead and donate?

How has donation affected your life in the short-term and long-term?
 For example, how has donating affected your health, employment, finances, and personal relationships?

Was donating worth it to you?
 Would you donate again?
 What would you change about the donation process?
 What do you wish could have been done differently?

Table 2
Forms of Living Donation

Kidney donation	One kidney (out of two that each person has) is donated
Liver donation	A portion (33%–66%) of a person's only liver is donated
Adult-to-adult	An adult donating to another adult
Adult-to-child	An adult donating to a child
Related donation	Donating to a person who is biologically related to the donor, e.g., sibling
Unrelated donation	Donating to a person who is not biologically related to the donor, e.g., spouse
Directed donation	Donating an organ to a specific person
Anonymous donation ("Altruistic" or "Good Samaritan")	Donating an organ to an unknown person
Paired chain exchange	As arranged by the transplant center, two or more donor-recipient incompatible pairs swap donors who are matches with the recipient of the other pair. This can occur when the donor and recipient do not have a compatible match of antigens
List exchange	Donating an organ to an unknown person on the waiting list in order to reduce the waiting time for a known person on the waiting list to receive an organ. This can occur when the donor and recipient do not have a compatible match of antigens

Table 3
Characteristics of Living Donors in the Special Issue¹

	Kidney	Liver
Successful, positive experience	Joos* [×] , McDaniel [^] Sauls, Wyatt, Yesawich*	Olenek
Successful, negative experience	Bauman, Young	Post
Successful, mixed experience	Jacobs, Altobelli* Adams [°] , Anonymous	Lewenstein
Unsuccessful	Flynn, Luebke Wright	Heath*

¹ All donors are related (directed), unless denoted by * to signify non-directed donors; [°] donation to a child, [^] Paired donation. [×] Chain donation; Bold: published in print, unbold: published online.

we could publish, deciding which to select for print was quite difficult. In selecting stories the editorial team prioritized the need to build a diverse collection of stories. Six additional stories appear as online supplemental material.

In this issue a four-fold goal evolved: (1) To improve the informed consent process for prospective living organ donors in the future by helping them to better comprehend the full range of risks of donation and the impact it can have on their lives. (2) To improve transplant clinicians' evaluation of potential donors. (3) To improve compassionate care of potential donors and after care for donors. (4) To illustrate the need for careful follow up with living donors to watch for future problems related to the donation.

I wish to thank the donors for contributing to this special issue and for their patience in working with the editorial team in developing their stories in depth. For many, this process was difficult because of the emotional turmoil it conjured up about their own or their recipient's evaluation process and health outcomes. Additionally, I recognize the courage of donors' to share insights about "the donors' role" as "living donor advocates" that challenge dominant and at times detrimental societal expectations about being positive about donation or 'heroic'. In addition, I thank all the transplant clinicians who assisted in soliciting stories including my colleagues at Northwestern University, the Gift of Hope (organ procurement organization (OPO) in Illinois), leaders in the American Foundation for Donation & Transplantation (formerly SEOPF) and the North American liver transplant social workers association, as well as listservs hosted by the National Kidney Foundation and the International Association of Living Organ Donors (Living Donors Online). Their assistance was instrumental to generating the necessary interest in contributing to this issue.

The commentators for this issue include a seasoned social scientist, Paul Wolpe, PhD, and a transplant clinician, Dianne LaPointe Rudow, PhD. Paul Wolpe is a sociologist and bioethicist and Director of the Center for Ethics at Emory University in Atlanta, Georgia. Dianne LaPointe Rudow is trained as a

Nurse Practitioner and is the Medical Director of the Liver and Kidney Donor Program Medical at The Mount Sinai Medical Center in New York, NY. Paul's commentary highlights the meaning of "giving the gift of life" for donors. Dianne's commentary focuses on the clinical aspects of donating including the psychosocial toll, need for more comprehensive follow-up, and limitations of the informed consent process. While the commentators discuss in depth the major themes and subtexts that donor stories illustrate, it is worth highlighting below some of the key themes of this special issue drawing upon the online narratives.

One theme emerged—certain side effects and complications that many donors experienced were not typically recognized, therefore, donors could not be adequately prepared in advance, thus undermining donors' informed consent. This pattern has been found in other studies which document that donors report experiencing unanticipated complications after surgery including greater pain or scar size than anticipated (Gordon et al., 2011). But in this issue, the narratives revealed various kinds of complications: bloating, depression, PTSD, and pain that derived from bodily positioning during the surgery. This information is important for driving the development of Patient-Reported Outcomes research based on these newly, or less commonly reported kinds of complications. In other words, these complications constitute additional donor outcomes that can and should be tracked as part of quality improvement (QI) efforts in transplantation designed to improve patient outcomes (Englesbe et al., 2006).

It is unnerving that many donors reported experiencing a wide array of health problems after surgical recovery, considering the fact that living donors are the epitome of health entering into the donation process. Living donors must be absolutely healthy to avoid any greater potential for harm as they undergo surgery. By virtue of their transformation into patients, donors are made vulnerable. As some donors noted, their perceived vulnerability appeared to have been exacerbated by the absence of ongoing care, concern, or follow-up by transplant centers. OPTN mandates that transplant centers follow living donors for a minimum of two years

after donation (OPTN/United Network for Organ Sharing, 2011). This regulation, in concert with the perception of donors as ‘healthy,’ may reinforce a short-term approach to donor care. Fortunately, in recognition of inconsistencies in transplant center follow-up of donors and donors’ continued health problems, policy-makers are currently discussing the prospect of extending donor surveillance (Living Kidney Donor Follow-Up Conference Writing Group et al., 2011). However, as Dianne LaPointe Rudow’s commentary notes, this may not be welcomed by all donors.

A number of other lessons were discerned from this special issue. For instance, support—both tangible and emotional—is needed for donors in addition to recipients, as Jacobs so well-articulated. Recipients should not rely solely on donors as caretakers in recovery, as donors may experience an even more difficult recovery and therefore require their own caretakers. Several donors maintained a highly optimistic view of the donation process, even in the context of adverse circumstances. For instance, some donors felt survival guilt. Other donors were spurred by optimism and religious faith in God, which for some, even bordered on evangelical zeal. Many advocated strongly for living donation while providing very practical guidance designed to empower individuals as they undergo living donation.

Yet other donors indicated that they felt that societal expectations and interactions with others made it impossible to obtain support for or legitimately complain about their experiences (Altobelli). There seems to be societal pressure on donors to maintain a Pollyanna outlook despite the hardship they may have gone through. The subtext of such societal pressures is the need to promote living donation with the interests of organ recipients in mind—negative comments may do a disservice to other patients awaiting a transplant and to the transplant field overall. It is this tension which heightens concerns about donors serving as a means to an end. Yet without open discussion, such pressures to voice only positive experiences will do a disservice to potential donors’ ability to be informed well enough to provide optimal informed consent.

Without support from loved ones or society more broadly, it is no wonder then, that many donors experienced psychological distress, as Dianne LaPointe Rudow eloquently summarizes.

Interestingly, the focus on helping a child overshadowed a donor-parent’s desire for information about long-term effects of donating. This observation is not unique as other donors have similarly been reported to downplay the risks of donation (Gordon, et al., 2011; Papachristou, et al., 2010). But this pattern raises a question about how well donors should appreciate information about donor risks. While some donors do not feel that information about risks influences their decision to pursue donation, others believe information is crucial for appreciating the significance of the impact of risks upon donors’ lives and criticized the transplant team for not adequately informing them of potential complications. It is unknown whether the positive and negative experiences of these various donors had any bearing on the importance they placed on being well informed.

CMS regulations require that a multidisciplinary team evaluates live donor candidates, (U.S. Department of Health & Human Services and Centers for Medicare and Medicaid Services, 2008) which suggest that donors undergo a thorough review. However donor stories reflect ongoing concerns about the effectiveness of the evaluation process. Hypothetically, if one were to conceive of living donation as a research protocol, no Institutional Review Board (IRB) would allow kidney removal as part of a research study. Such research would be construed as “a study no one would approve.” In other words, there are different standards of protections and safeguards implemented; but the difference is clear. Both participating in research and being a donor are voluntary actions, albeit, as some donors noted, not entirely, but the donor context involves immediate life and death ramifications. Thus, with more at stake and more to be gained (life), the clinical team’s allowance for donor risk-taking is greater in the donor context. Therefore it is incumbent upon transplant professionals and centers to ensure that donor evaluation is at least on par with the human protections exacted by an

IRB, comparable to the research context, to protect living donors from undue harm. Seen against this background, requests to enhance the consent process and protections for living donors appear supremely reasonable.

The narratives in this special issue are powerful. We hope these stories will broaden prospective donors' perspectives about donation, enhance transplant clinicians' and providers' (nurses, coordinators, and social workers) evaluation of and care for donors, and challenge societal expectations about how this population should be cared for before and *after* they undergo significant risks to save another's life.

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