

## Donor Outcomes Why We Need to Listen

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Recently there has been increasing appreciation of and emphasis on quantifying the long-term medical risks of kidney donation, including those of ESKD, hypertension, and pregnancy complications (1–5). These efforts are important and long overdue. Yet, there is still uncertainty about how to quantify kidney donor medical risks and what factors increase the likelihood of these complications. Not surprisingly, the focus of this work has been slanted toward medical outcomes, overlooking other potentially meaningful sequelae. Donors also face additional consequences, including financial and psychosocial burdens (6,7). Outcome studies have generally been designed and performed without the input of donors regarding which end points are the most important to them. In this issue of the *Clinical Journal of the American Society of Nephrology*, Hanson *et al.* (8) report on their work using focus groups to ask former donors in Australia and Canada about their experience donating and what outcomes are important to them.

Hanson *et al.* used a mixed-method approach to interview 123 donors in 14 focus groups across two Australian cities (Sydney and Melbourne) and one Canadian city (Vancouver). They used purposeful sampling to include donors of both sexes, across a wide age range, with varying time since donation, various relationships to the recipient, and a range of donation-related complications. They used nominal group technique to brainstorm on a list of outcomes, and then allowed individuals to rank the relative importance of the outcomes. Afterward, each group discussed the reasons for their rankings. They also used strong qualitative methodology to elicit and analyze participant opinions. The focus group transcripts were analyzed using a grounded theory approach for coding. Comparisons within and across groups were made.

Their work had some intriguing findings. Some of the responses (primacy of recipient outcome) are strikingly selfless. Many felt, what one participant is quoted saying, that “one of the key ones for me is the success of the donation for the [recipient].” This may be an illustration of both the type of people that self-select to be kidney donors as well as the relationship between the donor and recipient (*e.g.*, spouse, parent to child). Perhaps not surprisingly, donors characterized recipient graft failure as a particularly devastating outcome “similar to a stillbirth.” This speaks to the need to discuss

the possibilities of poor recipient outcomes with donors before donation, to stringently screen for appropriate living donor recipients and, with recipient permission, to inform potential donors when the recipient is particularly high risk.

The authors found that concerns over postdonation kidney function and kidney failure were ranked higher by Canadians than Australians. The authors pose a good set of possible explanations for this difference, including that there were more nondirected donors in the Canadian cohort and that the Canadian donor group was a more recent vintage. It seems counterintuitive that the Canadian donors would be more worried about kidney failure as there is a safety net for donors in Canada (higher priority on the wait list, as there is in the United States), but not in Australia. However, perhaps it is the very existence of the safety net that has caused the higher degree of concern. Learning that there is a priority on the wait list may send a subliminal message that postdonation kidney failure is a real problem rather than a theoretical one. The perceived reality of this potential complication may raise the level of concern.

The focus groups made clear that we need to do a better job of addressing donors’ emotional wellbeing postdonation. Although many donors reported an improvement in their emotional wellbeing and relationships, others had mixed or negative emotional experiences. Patient quotes, including “I was surprised to hear that you suffered depression. I wasn’t told that could be an impact and I think that’s really crucial. People really need to know that’s a possibility. I don’t remember them saying anything about it,” make clear that postdonation mental health is an issue that we as a transplant community need to acknowledge and address. In addition, nondirected donors may be more at risk because they do not directly benefit from the improved wellbeing of the recipient. Transplant programs need to educate all donors about potentially feeling let-down after donation, and offer nondirected donors additional acknowledgment and support postdonation.

Donors also reported wanting more information after donation. Participants voiced interest in learning more about how their own experiences compare with those of fellow donors. With comments such as “They are very good at the beginning at telling you this should

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happen. . . .Afterwards, my feeling on it, was they didn't really follow up with you and say did that happen?...They said the percentages of whatever but am I one of those percentages?" and "We're all adding to the data pool with our annual lab requisitions, but we don't hear back as a group on the overall experience. You've got a mass of data there. . . ." This message mirrors calls in the transplant community for better tracking and reporting of living donor outcomes. The donor's statement also serves as an important reminder that donor information should be made available not only to transplant professionals, but also to potential and former donors.

Hanson *et al.*'s work, although important, has some limitations. First, the authors reported using purposeful sampling, but we do not know how representative the groups were (compared with donors in those transplant units) or what the focus group participation acceptance rate was. It could be that a particular type of donor was more likely to agree to participate in the focus groups, thus biasing the narrative. For example, individuals without complications may have simply returned to their regular life or those with strong negative experience with donation may just want to put it behind them; or conversely, these outcomes, either good or bad, may have motivated them to participate. Second, the donors represented were largely women, white, and from major cities in Western countries. The sex balance is representative of the pool of living donors as a whole. However, racial and ethnic minority donors may have a different experience of donation because of a higher risk of complications, higher financial or psychosocial burden from donation, or different perception of risks (2,9,10). In addition, the concerns of living donors may vary by country (or even region within a given country) on the basis of access to support services including health insurance, primary care, family support, or mental health services.

An additional limitation, acknowledged by the authors, is that the focus groups were limited to individuals who successfully donated. The living donation process affects all of those who walk through the doors of our transplant centers, including those who rule-out, "opt-out," or are counseled out because of medical uncertainty or psychosocial burdens. These individuals face many of the burdens of a donor evaluation process that requires travel, multiple tests, missed work, and family responsibilities, but they do not receive the internal and social benefits of donation. Instead of being lauded as "heroes," they may worry about being perceived as failures. To attain a more comprehensive understanding of donor outcome priorities, discussions should also include potential donors who are still being evaluated as well as those who are awaiting a surgery date. Potential donors may opt-out of the process after hearing about potential outcomes. Also, considerations before donation may differ from those after the surgery is completed.

So, what can we take from this work? Using strong qualitative methodology and the donors' own words, this article beautifully illustrates that past donors also care about

nonmedical outcomes. Family life, life satisfaction, lifestyle restriction, and physical function are included in the top 15 donor identified outcomes, and rank above surgical mortality. More than anything, this work demonstrates that we cannot simply assume we know what donors care and worry about. We must talk with them about their priorities and concerns both before and after surgery. Although the study did not involve all donor stakeholder groups and thus cannot provide the entire story, thanks to Dr. Hanson and her team, an important conversation has begun.

#### Disclosures

None.

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See related Patient Voice and article, "Living Donation: The Donors and Recipient Perspectives," and "Identifying Outcomes that Are Important to Living Kidney Donors: A Nominal Group Technique Study," on pages 823–824 and 916–926, respectively.