

Living Donation The Donors and Recipient Perspectives

Maria E. Díaz-González de Ferris,¹ Lourdes M. Díaz-González,² and Michael Ted Ferris³

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We appreciate the opportunity to share our experience and express our thoughts on the work presented by psychologist Hanson *et al.* (1) from Australia and Canada that describes the short-term outcomes of kidney donors. Our comments reflect the effect that pediatric-onset ESKD has on patients and their families as well as our personal perspective as a donor-recipient team.

Our recipient was born at a time when prenatal ultrasound was a luxury, and a condition that is easy to diagnose prenatally was missed. Our son presented with sepsis due to a urinary tract infection at 18 months of age. His slow progression to adolescent-onset ESKD allowed time for our family to adjust to what was coming and identify potential donors. His multiple surgeries and complications afforded our family opportunities to ask questions of his wonderful providers and prepare . . . so we thought. What we were not prepared for was the effect that this condition would have on the siblings and the rest of our family. In the end, multiple emotions and concerns occurred during this process . . . similar to what Hanson *et al.* (1) reported. However, for us as donors, we learned to look at life in a different light, appreciate every moment that we have, and try to live life to its fullest with no regrets.

As a recipient, my experience was somewhat similar to those of individuals interviewed by Hanson *et al.* (1) as far as their expressed list of concerns. However, for me, my primary concern was that of the health outcomes for my three donors—above and beyond my own. Adverse health effects to the donors, regardless of my own outcomes, were my top concerns: physically, of course, but mentally as well. It did not occur to me to be concerned for my own health or my own outcomes; as a lifelong patient, I had experience and mental and emotional strength to draw from. Adverse outcomes for myself were to be expected and dispatched accordingly, but I was unprepared for how to deal with potential complications for my donors.

Now, onto the work by Hanson *et al.* (1). Their 14 focused groups allowed for the identification of 35 outcomes most important to 123 living donors in 2-hour meetings using monetary incentives. An importance score prioritized the outcomes ranked by participants. The authors used an adapted grounded

theory approach to identify outcomes and themes from these focused groups. Not all outcomes were identified by all groups, and not all participants ranked all outcomes.

The first thing that caught our attention was the age of the donors (27–78 years old), and the majority of participants donated <6 years before the study, with most <3 years. It would have been interesting to know the recipients' percentages of life with the disease as a proxy for time to make the decision to donate. It also would have been interesting to see an analysis on the basis of the relationship between the donors and recipients. The majority of participants were from big cities and women, and the most represented race was white. We also noted that most participants had completed high school or higher levels of education, had upper levels of income, and were employed and/or married, making us wonder about the responses by those not represented in this study.

The ten outcomes identified in the two study sites involve the surgery, kidney function, and effect on family, with life restrictions and life satisfaction ranking lower. This makes us wonder about the responses that donors with longer time postprocedure would have.

The work presented by Hanson *et al.* (1) was conducted in two countries where health insurance coverage is universal and health coverage long after the postoperative state is not an issue. We want to bring attention to the experience in one of the largest public children's hospital in México, where the donor is the recipient's roommate; therefore, pediatric nephrologists in conjunction with the transplant team take care of these adult donors. Although this assists with donors' health care coverage in the short term, in most cases, long-term coverage is not widely available. However, donation still takes place. The project by Hanson *et al.* (1) lays the foundation for work that needs to be extended to other countries, cultures, and settings.

We learned that our recipient would face ESKD early in his life. This gave our family time to prepare for the inevitable. Our experience may not represent the majority's point of views, because our recipient has received three organs (mother, father, and first cousin). However, the patient education for our donors was the same as for everyone in the transplant program. That meant a few hours of patient education and

¹Division of General Pediatrics and Adolescent Medicine, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina; ²Happy Heart Beats, Chapel Hill, North Carolina; and ³Altus Hospice, Austin, Texas

Correspondence:
Dr. Maria E. Díaz-González de Ferris, Division of General Pediatrics and Adolescent Medicine, The University of North Carolina at Chapel Hill, 231 MacNider Hall, Chapel Hill, NC 27599. Email: Maria_Ferris@med.unc.edu

signing surgery consents that were not literacy appropriate or user friendly. In the end, we share the same fears, questions, and hopes that all families affected by ESKD have, and we appreciate the opportunity to share our questions and concerns.

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Disclosures

None.

References

1. Hanson CS, Chapman JR, Gill JS, Kanellis J, Wong G, Craig JC, Teixeira-Pinto A, Chadban SJ, Garg AX, Ralph AF, Pinter J, Lewis JR, Tong A: Identifying Outcomes that Are Important to Living Kidney Donors: A Nominal Group Technique Study. *Clin J Am Soc Nephrol* 13: 916–926, 2018

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See related editorial and article, “Donor Outcomes: Why We Need to Listen,” and “Identifying Outcomes that Are Important to Living Kidney Donors: A Nominal Group Technique Study,” on pages 831–832 and 916–926, respectively.