

Being a Generalist and Donor Advocate: Seeing Both Sides of Transplantation

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Disclaimer: The names of patients as well as certain identifiers have been changed to protect privacy.

Every Tuesday, I have the good fortune of carrying out two of my favorite patient care responsibilities, making the jump halfway through the day from one end of the chronic disease management spectrum to the other. First, after finishing up a clinic session with my low-income primary care patients in the morning, I pull out of my clinic's parking lot next to the Discount Tire store. Second, 10 minutes later, I am at the expansive Duke Clinics, where I am the independent living donor advocate for individuals seeking to donate a kidney or liver. These two roles are fascinating and rewarding, presenting striking contrasts and similarities.

I knock on the exam room door and enter, seeing a fifty-something-aged woman seated with her husband, his arm draped behind her on the back of her chair.

I shake her hand: "Hi Ms. Brown. It's good to meet you. I'm the donor advocate for our transplant program and I'm going to do your medical evaluation for transplant. I'm also going to ask you some questions about how you decided to pursue becoming a donor. How has the day been so far?"

"Oh, long... but good," she says as she briefly peeks at her husband. The Browns have already been here for 5 hours—attending an educational session and getting labs and radiology tests. I'm the fourth member of the transplant team to interview her this afternoon.

Her husband speaks up, "We drove in from South Carolina last night. We're staying with Angela's sister. At dinner last night, she told

us her kidneys are only working about nine percent."

During my visit with the Browns, I have several items to assess. Does she understand the medical risks of donation and how to mitigate them? Is she at increased risk for coercion or false expectations about how the donation may affect herself and her intended recipient? "So, how did you originally find out that your sister needed a kidney?" I ask as I sit down in front of the exam room computer.

"Well, her husband was posting about it on Facebook, and I decided I had to call her. Her husband is a mess..." Her forehead creases. She tells me doesn't speak to her brother-in-law, whom she blames for her sister's poor health, and it was only in the last year that the two sisters reconnected. She worries that after the donation, her sister may continue her unhealthy choices. "What happens if *that* kidney stops working?" she wonders.

In addition to answering her questions, I have my own questions to answer during the visit. Is she psychologically well enough to take the risk of donation? Has she adequately explored how this might impact her job, her financial well-being and the people who may depend on her? Given her concerns, I may need to continue to counsel with her through the donation process. I give her my business card with an invitation to stay in contact with me with any questions along the way.

Coming from General Internal Medicine, I am somewhat atypical in the role of donor advocate, a task

which is often performed by nurses or social workers. I have this role because of the efforts of my division chief to improve collaboration with Duke's division of nephrology and transplant center. Each transplant center in the United States is required to have a donor advocate who is independent of the recipient's care team. The donor advocate visits with every individual who is being considered for living donation, a process which results in about 6,000 living donations yearly.¹ Fewer than one-fifth of the people who make it to the donor evaluation clinic eventually become donors, so the advocate's evaluation is an important part of narrowing the list. While striving to adequately assess the risk of each donor, my primary care experiences remind me repeatedly of the patients that I care for with renal failure who do not receive a transplant.

Earlier this morning in primary care, I saw Ruth McCammon. She is 66 years old and has been on dialysis for about 18 months now after having first arrived at the hospital struggling to breathe, her chest and legs swollen with fluid. She still does not have an arteriovenous fistula for dialysis due to some medical mishaps as well as her fear of the procedure.

Ms. McCammon came to her visit via paratransit van service. She gives a weary smile as I enter. "The bus came late, but I was out there early." I look out the window. It's a cold winter morning. "I was talking with my neighbor, John, and he said the nicest thing to me," she beams.

"He said: 'Ruth, I want to give you a

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kidney.’ He’s as old as me. I said to him ‘Nobody’s ever offered that to me, but you need to keep both your kidneys.’” Ms. McCammon’s grown children apparently never offered to donate to her.

Like her, many of my patients on dialysis have multiple reasons why they have not received a transplant: Some are elderly, and many do not have family who would be able or willing to donate. They come from racial minorities that are under-represented in the pool of living organ donors.² Finally, many of them are impoverished, with limited support structures in place. My management often consists of coordinating transportation concerns, reconciling medications with the pharmacy, and responding to requests for help from overburdened family members and caregivers. I don’t know if her providers even discussed transplant when she started dialysis given that they were managing repeated exacerbations related to her emphysema and diabetes. At the same time, Ms. McCammon was navigating an unstable housing situation.

In my two roles as a primary care physician and as a donor advocate, I need to understand the context of these two patients’ lives in their care. As a primary care provider, maybe I can be the one who helps Ms. McCammon see new possibilities—such as transplant or even just an arteriovenous fistula placement—for her end-stage

renal disease. As a donor advocate, I can help Ms. Brown sort out the ambivalence she feels about donation so that she can come to a decision that she will be able to look back on with a sense of peace. Understanding the medical facts is essential, but that’s only a small part of these complex discussions.

This larger picture includes understanding and recognizing both barriers and patients’ unique strengths and assets. Like Ms. Brown, transplant donors come from many miles away, often crossing state borders. The stories that they share are admirable, taking significant (and sometimes expensive) detours from their own busy lives to undergo medical testing and procedures that have no direct benefit to themselves. In each case, a prospective donor is making his/her valuable contribution to the wellbeing of another person. In thinking about Ms. McCammon and other primary care patients with renal failure, I try to understand how it is that they cope with the grinding experiences of managing end-stage renal disease. When I speak to her about getting a fistula for dialysis, her eyes flash and she crosses her arms. “No,” she says. She is understandably wary of procedures that she does not understand. Her strong sense of agency—frustrating to me in the moment—could be a valuable asset if she were to become a self-advocate for receiving a renal transplant. I believe that I

can help both patients channel these existing strengths.

Being a primary care provider and a living donor advocate puts me at opposite bookends of the medical experience. As general internists, we are constantly trying to look beyond the surface of our patients’ stories in order to troubleshoot the barriers they face and help them utilize their strengths. This perspective is often different from our subspecialist colleagues and will add value as we forge clinical and research partnerships with our transplant centers. Chronic renal failure is increasingly a fact of life in our society. Let’s find new ways to contribute and collaborate. Rewarding opportunities await us.

References

1. Organ Procurement and Transplantation Network. More than 30,000 transplants performed annually for first time in United States. <https://optn.transplant.hrsa.gov/news/more-than-30-000-transplants-performed-annually-for-first-time-in-united-states/>. Published January 9, 2016. Accessed January 25, 2018.
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