

Optimizing Use of Deceased Donor Kidneys Organ Waste While We Continue to Wait

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Walking into the transplant center each year to recertify for the kidney transplant list means more testing, more time off work for doctors' appointments, and more of the same—another year with diminishing hope.

The topic of discarded kidneys has gained a significant amount of attention because the supply of kidneys is not proportionate to the demand. As outlined in *CJASN*, an astonishing 5000 patients die on a yearly basis while waiting for a deceased-donor kidney. Approximately 5000 patients like me muster up the energy to maintain health insurance, meet guidelines for being considered “otherwise healthy,” and demonstrate psychology stability to remain on the transplant list, only to die during the fight.

In their abstract titled “A Donor Utilization Index To Assess the Utilization and Discard of Deceased Donor Kidneys Perceived as High Risk,” authors Brennan *et al.* (1) described their methods for establishing a means to assess utilization and discard of kidneys across several organ procurement regions. They conclude by indicating “there is marked center-level variation in the use of deceased donor kidneys with less desirable characteristics both within and between regions. There may be an association between utilization of these organs and shorter time to transplantation.” Although this written conclusion may seem rather inconclusive, they go on share statistics identifying variations in donor utilization indexes both within and across procurement regions. This is in line with discussions taking place within the kidney community.

I would imagine most patients such as me are not fully versed in the life cycle of organ procurement and transplantation. We rely on the experts to help translate these processes and I took to the internet to find out more. In a report published online in the journal *Clinical Transplantation* entitled “Report of National Kidney Foundation Consensus Conference to Decrease Kidney Discards,” recommendations were provided to decrease the number of kidneys discarded (2). These recommendations included practical measures ranging from improved communication, to improved crossmatching, to identifying specific centers that are more apt to accept at-risk kidneys.

The recommendations are spot on, but again they are simply recommendations. Who has the authority to instill accountability for those directly involved with and responsible for identifying potential donors and those saying “Yes, we'll transplant this kidney”?

As a patient with a panel-reactive antibody level of 100%, I can share so many stories on the emotional duress inflicted by a nearly 9-year wait on the transplant list. After the first 2 years, I put the possibility of receiving a transplant in the back of my mind. This was not done because I forgot about it. No, I was reminded each time someone would ask me “why haven't you gotten a kidney?” and each year I spent 2 days testing and visiting my transplant team. I put this out of my mind as a means of survival. I needed to focus on being as healthy as I could for my young children and not break down from the work involved in doing home dialysis.

After nearly 10 years on dialysis, I finally received a call for a transplant. I never vocalized this, but I thought for sure I would die on dialysis. An entire decade of hearing “a match will be tough” had taken its toll on me. But all along I assumed everyone—including my organ procurement organization, transplant center, and nephrologist—had done everything in their power to find a suitable match for me. Not once did it cross my mind that a match existed but was possibly discarded during the decade-long wait due to subjective views, biases, and risk avoidance.

My transplant failed after nearly 5 years, but I know those were the best years of my adult life. Although my creatinine never fell below three and I went through lots of hospitalization, dialysis, and treatments during the first 6 months after transplant; the experience was no comparison to the physical and mental pain I endured for 10 years on dialysis. I am back at square one, waiting for a transplant. This time I am wiser to the reasons I continue waiting, which extend beyond me being a difficult match. I sincerely hope the research continues, best practices are implemented, and accountability is enforced relative to discarded kidneys. I commend the organ procurement organizations and transplant centers that have the

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infrastructure and courage to limit the number of discarded kidneys. If only those organs could be associated with the face of a patient who (if even for just a few years) could get a reprieve from the needles, catheters, diet restrictions, fluid limitations, and frequent hospitalizations that become the norm for a patient on dialysis. Oh, how lives could be changed.

Disclosures

Ms. Bensouda is a Patient Ambassador for the American Association of Kidney Patients, an Advisory Board Member for the National Dialysis Accreditation Commission, and a Kidney Advocacy Committee Member and Program Committee Chair Member for the National Kidney Foundation.

References

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See related editorial, “No Time to Wait: Optimizing Use of Deceased Donor Kidneys,” and article, “A Donor Utilization Index to Assess the Utilization and Discard of Deceased Donor Kidneys Perceived as High Risk,” on pages 1560–1561 and 1634–1641, respectively.