Innovations and Policy

The medical evaluation, surgery, and hospital stay for the donor are covered by the recipient’s insurance. However, donors may experience out of pocket expenses that create an obstacle to donation. Financial resources to assist with travel and lodging expenses are available through the National Living Donor Assistance Center (1) and the American Kidney Fund (2). These resources are limited, and therefore, donors and recipients must meet eligibility criteria through means testing. Expansion of the National Living Donor Assistance Center to include non-directed donors and to eliminate or broaden means testing for recipients would reduce financial burden by allowing more people to access these resources (3). At this time, there is no mechanism for most donors to receive reimbursement of lost wages. This alone may be the most significant obstacle to living donation. Recommendations from the 2014 Live Donor Consensus Conference suggest that financial neutrality for living donors must be achieved for the number of living donations in the United States to increase (4).

What recommendations can you share to increase the likelihood of a living donor transplant?

Fonwahl: Here are some suggestions:

1. Early nephrology referral – I referred myself to a nephrologist when I had stage 3 chronic kidney disease (CKD). This early referral allowed time to arrange a preemptive transplant.
2. Knowledge of kidney function - Less than 10% of patients with stage 3 CKD are aware of their impaired kidney function. This means that 40% of patients initiate treatment in crisis mode and underscores the need for policies that reward early detection of CKD.
3. Dialysis versus transplantation – I do not believe that patients are fully informed of their life expectancy when they initiate dialysis. A history of transparency inhibits patients from seeking information on all available treatment options.
4. Medicare Part B ESRD benefit reform – The original intent of the Medicare Part B ESRD benefit was to ensure access to dialysis, which could then serve as a bridge to transplantation. Because of unforeseen demographic changes and financial incentives for dialysis treatment, dialysis is no longer just a bridge to transplantation but a final destination. Reform should include rewards for risk-benefit conversations, shared decision-making, and placing the patient at the center of care.

How does one find a living donor?

Reiner: Early engagement in the quest for a donor is critical. It is important for a recipient’s support team to come together and strategize about how best to communicate the need for a donated organ. Creating an advertisement explaining the need for a donor that can be sent out via an email chain and using social media to spread the message can be very effective tools in this campaign.

How can the transplant community increase living donation?

Reiner: Many people are not aware of what kidney donation entails. They do not realize this is something that ordinary people are doing. It is important to be knowledgeable about all of the steps in the process to answer any basic questions. Understanding the process helps potential donors be more comfortable in taking the next step: calling the transplant center.

Charlton: The key component in overcoming real and perceived barriers to living donation is early access to the evidence-based education of transplant professionals who can provide guidance, recommendations, and support to allow the potential donor to proceed.

Kevin Fonwahl is president of The Voice of the Patient. Marian Charlton, RN, is chief transplant coordinator at Weill Cornell Kidney and Pancreas, The New York–Presbyterian Hospital/Weill Cornell Medicine Center. Mendy Reiner is founder and chairman of Renewal in Brooklyn.

References


Improved Transplant Outcomes for Children with FSGS

Children with focal segmental glomerulosclerosis (FSGS) who undergo kidney transplantation are at high risk of recurrent disease and allograft failure. A new study provides insights into long-term post-transplant survival for this group of patients.

The retrospective study in American Journal of Kidney Diseases included 12,303 pediatric patients receiving a first kidney transplant from 1990 through 2009, identified from the US Renal Data System database. In 11% of patients, FSGS was the primary cause of end stage renal disease. All-cause mortality and allograft loss were compared for patients with FSGS versus other causes. All-cause mortality for children with FSGS improved significantly from the 1990s to the 2000s: from 12.24 to 6.72 deaths per 1000 patient-years, hazard ratio (HR) 0.55. These children also had a smaller but still significant reduction in allograft loss: 75.91 versus 89.05 events/1000 patient-years, HR 0.85. With adjustment for baseline characteristics at transplantation, mortality was similar for children with and without FSGS. That was so despite higher rates of allograft loss for those with FSGS: HR 1.27 in the 1990s and 1.17 in the 2000s. But additional analysis of children transplanted in the 2000s, adjusted for allograft cause as a time-varying covariate, found lower mortality in the FSGS group: HR 0.70. The results showed that survival improved for children and adolescents with FSGS undergoing kidney transplantation from the 1990s to the 2000s. In the more recent period studied, the 2000s, posttransplant survival for children with FSGS was similar to that for children without FSGS, and may be even better after adjustment for allograft failure.

“Such that allograft loss is a potential mediator of patient survival in FSGS, and that a focus on interventions to decrease allograft loss due to disease recurrence may improve patient survival,” the investigators conclude.


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