Virtual Mentor
American Medical Association Journal of Ethics
March 2012, Volume 14, Number 3: 190-193.

ETHICS CASE
Should a Nonadherent Adolescent Receive a Second Kidney?
Commentary by John D. Lantos, MD, and Bradley A. Warady, MD

Carl is 17-1/2 years old and has familial nephrotic syndrome due to focal segmental glomerulosclerosis. His sister also developed renal failure; she underwent hemodialysis and then transplantation. Carl had observed that her quality of life was much better after transplantation.

Carl's mother died when he was an infant. His father has mental health problems and struggles to cope with those and his two chronically ill children.

The nephrology team was worried about Carl's ability to comply with a posttransplantation medication regimen, but nevertheless proceeded with a preemptive (i.e., without prior dialysis) transplant when Carl was 14 years old and showed signs of impending renal failure. He had excellent graft function for 9 months, but then experienced acute and, later, chronic rejection due to suspected, but not admitted, nonadherence to medications. He began dialysis the next year. His course on dialysis has been complicated by frequent episodes of fluid overload, hyperkalemia, and hyperphosphatemia. He also has exaggerated fistula pain. He remains short in stature.

Carl does not want to continue on dialysis and has repeatedly asked the nephrology team to list him for another deceased-donor transplant. The health care team has severe reservations about listing him for a second transplant because of the history of presumed medication nonadherence and his ongoing management issues during dialysis. No living-related donor is available.

Commentary
One of the most common causes of graft failure after a kidney transplant in adolescents is nonadherence to posttransplant immunosuppression medication. In a recent review, Rianthavorn and Ettenger noted the frustrations that this engenders among nephrologists: "adolescents enjoy the best 1-year graft survival of any age group. However, the long-term transplant outcome in adolescents is disappointing. Nonadherence with immunosuppressive medications is one of the most important contributing factors for graft rejection and loss in teenagers" [1]. In order to be successful, renal transplantation requires the teenager to follow a complex medication regimen which includes multiple immunosuppressive agents that must be taken on a prescribed schedule to prevent rejection. The use of some of the medications may be associated with cosmetic side effects. Many teens have

difficulty with this, fail to take their medications as recommended, and, as a result, their grafts fail.

The phenomenon of nonadherence among teens creates ethical dilemmas about the appropriate treatment of end-stage renal disease (ESRD) in the adolescent patient population. Though kidney transplantation is the preferred treatment in most cases, the chances of graft failure in this population are high, and kidneys for transplantation are a scarce resource. There is a long waiting list for deceased-donor kidneys [2].

In most cases, teens with ESRD can be treated with dialysis. Some argue that this is the better approach since it allows them to mature and to then get transplants when they are psychologically more capable of adhering to a complex medication regimen. Additional neurocognitive development may also result in a better understanding of the consequences of treatment nonadherence. (Even then, they, like other transplant patients, need support from family or social service agencies.)

However, delaying transplantation is not without costs. Transplantation is less successful for patients who have been on dialysis than for those who have not [3]. The best time to do a kidney transplant is early in the course of ESRD.

Ethical Analysis

Fundamental ethical principles conflict in a case like this. The principle of respect for autonomy would demand that we honor the patient's wishes, values, and preferences. Carl can be treated with either dialysis or transplantation. He would prefer transplantation. He clearly understands what it means to have ESRD and be on dialysis. He understands this as a result of his own experience and as a result of seeing his sister's responses to these different modalities of therapy.

The implications of the principle of beneficence are not straightforward in this case. On the one hand, transplantation would most likely lead to better outcomes for the patient than continued dialysis. But that would only be true if the transplantation were successful, and it would only be successful if the patient adhered to the complex posttransplant medication regimen. If he could not do so, and the graft failed, he could be worse off than if he had continued dialysis and not received a transplant. Transplant rejection and attempts at reversal can lead to hypertension, weight gain, fluid retention, infection, absence from school and work, impaired quality of life, and persistent poor kidney function, Also, further antibody formation might adversely affect Carl's ability to ever obtain another transplant.

Dialysis might be the better option for Carl at this point in his life because it would buy some time for him to mature and to better understand his condition and the implications of medication nonadherence. This might lead to a higher chance of posttransplant success in the future. However, his prognosis may be worse if he remains on dialysis for a long period of time.

Considerations of justice lead us in a different direction, requiring us to ask not just what the patient wants, or what the doctors thinks would be best, but, instead, what is most fair. There is an absolute shortage of deceased donor kidneys. The number of patients on the national waiting list in the U.S. for a deceased donor transplant has risen from 41,177 people in 1999 to 76,089 people in 2008 [4]. Given the number of people waiting for a transplant, justice demands that cadaveric organs be preferentially allocated to recipients for whom they would be most beneficial. Patients who are at high risk for nonadherence and graft failure thus should not get high priority. These sorts of considerations, however, require that doctors ignore their patients' preferences and their own medical judgment of what is best for the individual patient.

Evaluating the Likelihood of Nonadherence

Nonadherence to medical treatment is a well-recognized problem in adolescents that arises not just in renal transplantation but in many other clinical situations. It has been described in the treatment of cancer, cystic fibrosis, seizures, diabetes, asthma, and many other clinical conditions. The unique problem in ESRD is that there are two standard approaches to treatment that have different implications for quality of life, different requirements for adherence and consequences of nonadherence, and different implications for justice. In evaluating which of these is best for any particular patient, physicians must consider both short-term and long-term outcomes.

It would be inappropriate to give a teenager a kidney if the odds of graft survival were low. This would not only be a poor allocation of scarce resources, it would also be dangerous for the teen, as noted above. It would be equally inappropriate to deny a teenager access to a transplant simply because he was judged on the basis of age to be at high risk for nonadherence.

The best approach in this situation is to make an individualized assessment of the barriers to adherence, the likelihood of nonadherence, and the potential benefits of interventions that might improve adherence. In this case, since the patient is already on dialysis, his ability to adhere to the demands of that regimen might be considered a "trial of therapy" that will give information about the likelihood that he would adhere to posttransplant treatment. He should be given clear instructions about what is expected of him, feedback whether or not he adheres to the demands of dialysis, and an endpoint to this "trial of therapy." If he is able take medication, manage his diet and fluids, and keep his appointments in clinic and in dialysis, then he should be eligible for a second transplant.

References

1. Rianthavorn P, Ettenger RB. Medication non-adherence in the adolescent renal transplant recipient: a clinician's viewpoint. *Pediatr Transplant*. 2005;9(3):398-407.
2. Ashby VB, Kalbfleisch JD, Wolfe RA, Lin MJ, Port FK, Leichtman AB. Geographic variability in access to primary kidney transplantation in the United States, 1996-2005. *Am J Transplant*. 2007;7(5 Pt 2):1412-1423.

3. Kessler M, Ladriere M, Giral M, et al. Does pre-emptive kidney transplantation with a deceased donor improve outcomes? Results from a French transplant network. *Transpl Int*. 2011;24(3):266-275.
4. Axelrod DA, McCullough KP, Brewer ED, Becker BN, Segev DL, Rao PS. Kidney and pancreas transplantation in the United States, 1999-2008: the changing face of living donation. *Am J Transplant*. 2010;10(4 Pt 2):987-1002.

John D. Lantos, MD, is a professor of pediatrics at the University of Missouri-Kansas City and director of the Children's Mercy Bioethics Center at Children's Mercy Hospital in Kansas City. His latest book, *Controversial Bodies,* explores ethical and religious issues associated with the public display of plastinated corpses in exhibitions such as *Body Worlds.* He is a former president of the American Society of Bioethics and Humanities.

Bradley A. Warady, MD, is a professor of pediatrics at the University of Missouri-Kansas City School of Medicine and chief of nephrology and director of dialysis and transplantation at The Children's Mercy Hospitals and Clinics. He is senior editor of the book *Pediatric Dialysis*.

Related in VM

Contemporary Debates over the Acceptability of Kidneys for Donation, March 2012

Rationing Livers: The Persistence of Geographic Inequity in Organ Allocation, March 2012

Liver Transplantation: The Illusion of Choice, March 2012

The Veneer of Altruism, March 2012

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.