Reducing the Shortage of Transplant Kidneys: A Lost Opportunity for the US Health Resources and Services Administration (HRSA)

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Note from Editors: Given the importance and controversial nature of this topic, a diversity of viewpoints is critical. For this reason, AJKD solicited a commentary on this editorial from Danovitch, Capron, and Delmonico, whose counterpoint appears in the accompanying Policy Forum Commentary (p. 967).

During the past 3 decades in the United States, tens of thousands of patients with kidney failure have died while awaiting transplantation owing to a shortage of transplant kidneys. The President’s July 2019 “Executive Order on Advancing American Kidney Health” included 2 sections specifically aimed at increasing kidney transplantation. Section 7 directed the Secretary of Health and Human Services (HHS) to propose regulations to increase the recovery of deceased donor organs and reduce discards, and section 8 directed the Secretary to reduce financial barriers to living organ donation.

The 2 agencies of HHS that are responsible for implementing these life-saving sections responded in very different ways (Box 1). The Centers for Medicare and Medicaid Services (CMS) made a serious attempt to comply with both the letter and the spirit of section 7. However, the Health Resources and Services Administration (HRSA) made only a perfunctory response to the much more important section 8. In its recently issued final rule, HRSA did not go beyond the modest changes suggested in the executive order, which we estimate will increase kidney donations in the neighborhood of only 2,000 per year. If HRSA had taken a more expansive view of its mandate—as CMS did—and modified its rule as we suggest below, we estimate it could have increased kidney donations in the neighborhood of 15,000 per year. This means about 13,000 additional kidney failure patients a year could have lived significantly longer and healthier lives.

Deceased Donors

In December 2019, CMS issued a detailed report regarding section 7 that proposed replacing 3 existing metrics for organ procurement organization (OPO) performance in recovering the organs of deceased donors with 2 new measures: donation rate and organ transplantation rate. Every 4 years, OPOs would have to meet CMS requirements for both rates. Indeed, CMS proposed that all OPOs perform at or above the current 75th percentile. These new rules will apply much-needed regulatory pressure on OPOs to increase the number of organs recovered. However, the rules represent a challenge to existing OPOs, and were met with extensive concern by much of the transplant community.

Financial Barriers to Living Donors

In contrast to the detailed CMS proposal on recovering organs from deceased donors, HRSA made only a perfunctory response to section 8 of the executive order concerning living donors. In September 2020, HRSA issued a final rule—"Removing Financial Disincentives to Living Organ Donation"—that laid out the additional donor expenses that the government will reimburse (beyond the travel and lodging expenses that are already reimbursed). The list did not go beyond those expenses specified in the original executive order—lost wages, child care, and elder care.

Also in September, HRSA issued a final notice, “Reimbursement of Travel and Subsistence Expenses Toward Living Organ Donation Program Eligibility Guidelines,” in which it proposed increasing the ceiling on income that donors and recipients can earn and still be eligible to have the donor’s expenses reimbursed. HRSA raised the eligibility threshold from 300% of the HHS poverty guidelines to 350%. The latter number is far below the 500% recommended by both the National Living Donor Assistance Center and the Advisory Committee on Organ Transplantation (which provides recommendations to the Secretary of HHS on organ transplantation).

Taken together, we estimate these 2 responses of HRSA will only increase kidney
donations in the neighborhood of 2,000 per year (an increase of only 9% of the 23,401 donations in 2019). This result falls far short of the goal set by HHS Secretary Alex Azar, who stated: "On living donations, we’re going to dramatically expand support for living kidney donors, so that Americans who wish to be generous living donors don’t face unnecessary financial barriers to doing so” and “When an American wishes to become a living donor, we don’t believe their financial situation should limit their generosity.”

Thus, HRSA seems to have missed an opportunity to markedly increase the supply of donor kidneys. About 13,000 kidney failure patients a year could have enjoyed significantly longer and healthier lives if HRSA had modified 2 key parts of its initial (December 2019) proposal as we suggest below.

**Removing Disincentives Would Save the Government Money**

In the “Summary of Impacts” section of its initial proposal, HRSA stated: “While expanding the list of expenses eligible for reimbursement for living organ donors will increase the average amount of reimbursement, the federal government can expect to save overall due to an increase in additional organ transplants performed and the aversion of dialysis.” We strongly support this view. The key point is the government is already committed to paying for dialysis therapy for most patients with kidney failure, and that therapy is much more expensive than the cost of a transplant. Therefore, if the government spends a relatively small amount to remove financial barriers to kidney donation, and that causes more transplants to occur, then the government will spend less money on very expensive dialysis therapy, so it will save money in the long run.

Although it is clear from the quote above that HRSA well understands this reasoning, it surprisingly failed to apply it when it raised the income limit on the donors who are eligible for government reimbursement to only 350% of the poverty guidelines. If it had followed its own logic, it would have concluded that, from the viewpoint of the government budget, the limit should be raised to 500% or even higher (assuming wage reimbursement is capped at $10,000, as advocated in our previous work). This is because the savings from stopping dialysis are so large that they would exceed the cost of a transplant, even including the slightly larger reimbursement costs of affluent donors. (For the arithmetic supporting this statement, see the left-hand column of Table 3 in Held et al.) So the more donors—rich or poor—whose expenses are reimbursed by the government, the more money the government would save in the long run.

**Additional Barriers to Organ Donation**

In the discussion section of its initial proposal, HRSA invited comments on additional financial barriers to organ donation that it might remove. In our earlier empirical research, we detailed 7 disincentives facing living kidney donors, the magnitude of which totaled almost $38,000: (1) cost of travel to, and lodging at, a transplant center; (2) loss of income while recovering from surgery; (3) cost of dependent care while recovering from surgery; (4) risk of dying during surgery; (5) pain and discomfort of surgery; (6) decrease in the long-term quality of life due to kidney removal; (7) concern that a relative or friend might need the donor’s kidney in the future.

HRSA has already removed the first disincentive, but only for low-income donors and recipients, by
reimbursing donor expenses through the National Living Donor Assistance Center. Now, in response to section 8 of the President’s executive order, HRSA will do the same for the second and third disincentives.

In our previous analysis,8 we suggested HRSA also remove disincentives 4 through 7, and reimburse donors of all income levels. Specifically, to remove disincentives 4 and 6, HRSA should provide an insurance policy covering death, disability, and long-term health problems due to donation. To remove disincentive 5, HRSA should give donors a tax credit of $6,500. And to remove disincentive 7, HRSA should promise to provide a kidney for a specific person in the future (ie, give them a voucher) in return for the donor donating a kidney today.

If the government removes all of these disincentives, it would not only be a major step toward economic fairness, but it would also significantly increase the number of living donors. The very limited evidence available on the latter effect suggests that if the government removes all 7 disincentives, with a total magnitude of almost $38,000, the number of kidney donations from living donors would increase in the neighborhood of 15,000 per year. (It should be emphasized there is considerable uncertainty surrounding this estimate, since it is based on only a small number of historical examples.) This would raise total kidney donations (from both living and deceased donors) from about 23,500 in 2019 to about 38,500 per year. In contrast, we estimate HRSA’s final rule would increase kidney donations in the neighborhood of only 2,000 per year, raising total transplants to only about 25,500 per year.8

Ethical Considerations

The primary ethical argument in favor of having the government remove all 7 disincentives and substantially raising the income limit on donor eligibility for reimbursement is that it would increase kidney donations from living donors, enabling tens of thousands of kidney failure patients to obtain transplants and live longer and healthier lives. A second ethical consideration is economic fairness. Donors should not be penalized for their generosity. They should not suffer any economic loss because they have donated a kidney; rather, they should be made whole again.

However, this is not the dominant view of the transplant community. That view is expressed in the Declaration of Istanbul, which has been endorsed by more than 100 countries.9 The declaration states: “Organ donation should be a financially neutral act.” Although the declaration does not define financial neutrality, a group of experts have undertaken that task.10 Their definition specifically excludes “pain and suffering” and “household chores” as reimbursable expenses. Thus, if the US government were to follow the advice of the declaration, it would not remove disincentive 5 (pain and discomfort of nephrectomy) and part of disincentive 3 (dependent care), but it would remove the other 5 disincentives. Although doing so might not increase the number of kidney donations by 15,000 (the gain we estimate resulting from removing all 7 disincentives) it would still be much closer to that number than the gain of 2,000 we estimate would result from HRSA’s final rule.

Article Information

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