

Opportunities to Increase Availability of Deceased Donor Kidneys

Richard N. Formica Jr.

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In this issue of the *Clinical Journal of the American Society of Nephrology*, Cohen *et al.* (1) report that receiving a kidney from a diabetic deceased donor versus remaining on the waiting list is associated with better patient survival. This important study provides data to support the use of deceased donor kidneys that are likely to be discarded. However, as important as this finding is, it is necessary to view it in the context of the larger problem facing the nephrology community as it struggles to care for patients with ESRD.

In 2015, approximately 30,000 persons were added to the waiting list for a kidney transplant, 5000 died while waiting, and 4000 were removed from the list because of a deteriorating medical condition (2). Dialysis therapy for ESRD is only a temporizing measure, and patients have such a high mortality rate that cancer screening does not result in years of life saved (3). However, despite the poor patient outcomes associated with ESRD, in 2011, the United States spent \$34.3 billion, which was 6% of the Medicare budget, on ESRD-associated therapies (4). Only a small percentage of these dollars was spent on kidney transplantation, despite the fact that it is the superior treatment option and results in increased longevity and improved quality of life (5). Moreover, compared with dialysis, providing transplant care costs much less per year of treatment (6,7). Given the magnitude of the health care crisis posed by ESRD and its toll in terms of human and financial costs, it is unfortunate that, despite spending 17% of its gross domestic product on health care (8), the United States does not focus more of its resources on solving the problem through increasing access to kidney transplantation.

The mismatch between the need (2) for donor organs and their availability (9) is striking. Although the rate of organ donation has been trending up, it has not kept up with the need (9). However, should it be this way? A recent study conducted by the Organ Transplantation and Procurement Network estimated the number of persons who die each year in a manner that makes them possible organ donors to be 38,000 (10). This is dramatically more than the 9080 deceased donors in 2015 (9). Although this potential number is on the basis of several assumptions that may lead to an overestimation, the gap between potential and actual donors cannot be ignored. The number of 38,000 must be viewed in the context of its potential effect on the deceased donor kidney transplant waiting list. Conservative estimates place the percentage

of the adult United States population registered as an organ donor at 51% (11). Therefore, assuming that registered donors are spread equally over the number of potential donors identified in the study, this would potentially amount to 19,000 donors or 38,000 donated kidneys per year. The current waiting list for a deceased donor kidney stands at just over 100,000, with anywhere from 60% to 70% of individuals active on the list. Said bluntly, if only one half of the potential donors donated, it would substantially reduce the waiting list for kidney transplantation in 2 years' time.

The work by Cohen *et al.* (1) adds to the many laudable efforts to both increase the number (12) and improve utilization of deceased donor kidneys (13,14). The Organ Donor Breakthrough Collaborative partnered hospitals with organ procurement organizations in an effort to develop best practices for increasing organ donation. This effort has successfully increased the number of donated organs from 6190 in 2002 to almost 10,000 in 2015 (12). In addition, there are numerous efforts to improve the utilization of the over 3000 kidneys that are recovered each year for transplantation and discarded (15). Initiatives, such as the Health Resources and Service Administration Collaborative Innovation and Improvement Network, and the work by Cohen *et al.* (1) focus on using kidneys viewed as marginal: those kidneys from older donors with other medical conditions, such as hypertension and diabetes, that result in less than ideal kidneys for transplantation (14). These are important steps, but such kidneys are associated with worse overall outcomes and must be allocated to the appropriate recipient. Estimates suggest that this may add only incrementally more kidneys per year (15). Additionally, the kidney allocation system was recently overhauled in an effort to better match kidneys with recipients, thereby improving the longevity of a transplanted kidney and reducing the need for a second kidney transplant, which will reduce future demand (13). All of these efforts are well intentioned and important, and yet, all are merely nibbling at the edges of a much larger problem, which is that there are too few organ donors and too many people in need of a transplant.

Over the past 20 years, there has been a successful effort to educate the public about the need for organ donation. These efforts have been successful; as of September of 2016, 51% of adults, 130 million people, are registered as organ donors, and 95% of the population

Departments of
Medicine and Surgery,
Yale University School
of Medicine, New
Haven, Connecticut

Correspondence:

Dr. Richard N.
Formica Jr., Yale
University School of
Medicine, Internal
Medicine, Boardman
124, PO Box 208029,
330 Cedar Street, New
Haven, CT 06520-
8029. Email: richard.
formica@yale.edu

support organ donation (11). These statistics show the public's acceptance of organ donation. However, this also highlights a fundamental disconnect. With so many people voicing their support for organ donation, why has the number of donors remained comparatively stagnant for so many years? If the United States is to confront the public health crisis of ESRD, it must think differently about the process of deceased organ donation.

Fortunately, there exists a template of a successful approach to be considered. It is the policy of presumed consent for organ donation (16,17). In a presumed consent system, also known as opt out, individuals are required to affirmatively declare they do not want to be a donor. Although the data do not prove causation, every country that has successfully enacted presumed consent laws has had sizable increases in the rate of organ donation. Admittedly, there are arguments why this approach may be too difficult for the United States and could potentially lead to a decrease in the number of organ donors. Nevertheless, the challenges of enacting change should not be a reason for stifling consideration of alternative approaches. At a minimum, the process of thoughtful discussion of alternative approaches may lead to new ideas.

It is reasonable to question why, when one half of the United States adult population is already registered as an organ donor, this approach would lead to a significant change. One reason is that it would alter the paradigm of the request for organ donation. A presumed consent approach to organ donation would allow for the evaluation of a potential donor to begin automatically. This approach does not need to culminate in "donation at all costs," but rather, it would allow the family to be approached with an affirmative statement of "this individual is suitable as a donor; do you know of reasons why they would not want to donate" versus a passive statement of "do you know if they wished to be an organ donor." The latter statement places the burden of ambiguity on the family, and the presumed consent approach allows the family to let a medical decision proceed unless they know of concrete reasons for it not to; also, it removes the burden of responsibility from them.

There are cultural challenges to enacting presumed consent in the United States, and although not the only reason, religion is the one that can be addressed with qualitative data. Although not monolithic in thought about this topic, all of the major religions of the world either directly support organ donation as consistent with their philosophy or acknowledge it as good act and allow the individual to reconcile it with their personal beliefs (18). Regardless of where someone is on the spectrum of belief about organ donation, an opt-out approach does not jeopardize their self-determination. An affirmative opt out would be respected as a binding decision just as the affirmative opt in. Moreover, in the absence of an affirmative opt out, information from the family that organ donation is not consistent with the deceased's religious beliefs or personal wishes would serve as proof of the lack of the individual's intent to donate his/her organs. In the absence of "donative intent," the principles of established gift law—the law on which organ donation rests—are not met, and donation cannot proceed (19). It is important to emphasize that presumed consent, although not as intuitively fitting into the construct of gift law, can, under the correct legal framework, be consistent with its underlying principles (19).

For presumed consent to work in the United States, it would require leadership and civic responsibility from many parties. It is equally important to achieve affirmative public consensus, because it has already been shown that, if presumed consent is enacted in a country with a population that does not accept it, it will fail (20,21). The first step will be for legal scholars to resolve whether it violates constitutionally granted rights and is permitted under state law as prescribed by the Uniform Anatomical Gift Act (22,23). If legally permitted, politicians would need to modify, enact, and support laws to allow presumed consent. Media organizations would need to forgo publishing sensationalized anecdotes of donations felt to have gone poorly, and the medical profession must embrace the approach and present it to patients in a manner that is devoid of editorial comment. Finally, public monies will be needed to mount an educational campaign to inform the public of the societal need for this approach and why it is in the best interest of everyone.

The United States is facing a health care crisis of ESRD, and each year, people die for no other reason than lack of access to kidney transplantation. Certainly, this crisis must be addressed on many fronts: improved population health, earlier identification of precritical disease, advancement in pharmacologic therapy, and novel biomedical and technological approaches. As important as all of these are, they remain in the future, and the need is now. Presumed consent may not be a viable option in the United States; however, the current conversation about how to solve the crisis of too many people in need of a kidney and not enough available organs must expand beyond the comfortable topics of reducing organ discards and increasing living kidney donation. By venturing into the uncomfortable and difficult, we challenge ourselves to rethink the problem, and this can lead to as yet unconsidered answers.

Disclosures

None.

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