

favor of other ethical commitments. I admire Steinberg's revolutionary spirit and his commitment to justice. I simply want our efforts to start locally so that national efforts are more meaningful and fair. ■

## REFERENCES

Alexander, G. C., and A. R. Sehgal. 1998. Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor. *Journal of the American Medical Association* 280(13): 1148-1152.

Ayanian J. Z., P. D. Cleary, J. S. Weissman, and A. M. Epstein. 1999. The effect of patients preferences on racial differences in access to renal transplantation. *New England Journal of Medicine* 341(22): 1661-1669.

Callender, C. O., and P. V. Miles. 2004. Institutionalized racism and end-stage renal disease: Is its impact real or illusionary? *Seminars in Dialysis* 17(3):177-180.

Davis, C., and G. Randhawa. 2004. Don't know enough about it!: Awareness and attitudes toward organ donation and transplantation among the Black Caribbean and Black African Population in Lambeth, Southwark, and Lewisham, United Kingdom. *Transplantation* 78(3): 420-425.

Levenson, J. L., and M. E. Olbrisch. 2000. Psychosocial screening and selection of candidates for organ transplantation. In *The Transplant Patient: Biological, psychiatric, and ethical issues in organ transplantation*, ed. P. T. Trzepacz and A. D. DiMartini. New York: Cambridge University Press.

Roberts, J. P., R. A. Wolfe, J. L. Bragg-Gresham, et al. 2004. Effect of changing priority for HLA matching on the rates and outcomes of kidney transplantation in minority groups. *New England Journal of Medicine* 350(6): 545-551.

Spital, A., and W. J. Wendt. 2004. Letter to the editor. *New England Journal of Medicine* 350(20): 2095.

Steinberg, D. 2004. An 'opting in' paradigm for kidney transplantation. *American Journal of Bioethics*. 4(4): 4-14.

United Network for Organ Sharing (UNOS). Organ distribution: Allocation of deceased kidneys. Available from: <http://www.unos.org/policiesandbylaws/policies.asp?resources=true>.

Veatch, R. M. 2000. *Transplantation ethics*. Washington, D.C.: Georgetown University Press.

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## Reasonable People, Double Jeopardy, and Justice

Sara Goering, University of Washington

Annette Dula, University of Colorado

In his article "An 'Opting In' Paradigm for Kidney Transplantation" David Steinberg proposes to address transplant organ scarcity issues by formulating an opt-in system that rewards those who agree to donate their organs when they are deceased with preferential treatment should they need organs for transplant during life (Steinberg 2004). While we find this proposal intriguing, we recognize several serious limitations that the author does not address sufficiently. Our concerns highlight the problem of addressing the scarcity through a paradigm that focuses on idealized rational individualism, and point to serious issues of justice. As a consequence, we reject the proposal. Because we agree with the author's moral concerns with life donation programs, we briefly recommend other options for addressing the scarcity problem.

Our main concern is with Steinberg's claim that the opt-in proposal presents "an opportunity a rational person should willingly accept as very attractive" (Steinberg 2004, 10). We disagree. We recognize that on the face of it, the "rational person" claim appears reasonable: a person who opts in has nothing to lose except organs after she dies, and everything to gain should she need an organ to improve the

quality of her life or to save it. But this initial framing only applies to a narrow, idealized picture of the rational agent. It ignores the range of rational beliefs about organ donation, and it presumes an ideal system of health care delivery in which all are treated equally. In so doing, it quietly shifts extra burdens to those who are already not well-served by the current health care system.

Individuals may have many and varied reasons for not wishing to opt in to the organ donation pool, and not all of them are irrational. We are particularly concerned about individuals from disadvantaged ethnic minority groups. What the author describes is a proposal that would work well either in an ideal system of health care delivery, or for those already well-situated in this society. Unfortunately, his proposal would be implemented in a world where bias in the delivery of health care is a matter of fact, supported by numerous scholarly and medical publications documenting unfair, unequal, and inferior health care for African Americans, as well as other ethnic minorities (Institute of Medicine 2002). Given this disparity in health care, as well as the legacy of cultural distrust of the medical system including but going far beyond the Tuskegee syphilis

study (Dula 1994; Thomas and Crouse Quinn 1994), we venture to guess that most African Americans and other ethnic minorities would probably not opt in to the donation system, believing that there is a reasonable chance they will not be fairly treated, even if they are purportedly given preferential status on the UNOS list. Indeed, many members of the African American population have not signed organ donor cards in the current system, given the fear that they will not receive life-saving care if their organs are needed elsewhere (Callender et al. 1994). Community focus groups suggest that many African Americans worry that if they sign the card, they will be allowed to die or even killed in order to provide organs for others considered more valuable. Such beliefs will likely translate into reluctance to join the proposed opt-in system, which may be considered a trick to get organs for white people, given the widespread and historic distrust among African Americans.

Although some may view this reluctance as a sign of irrational fear, the history of discrimination and medical abuse against African Americans in the U.S. health system (Gamble 1997; King 1992) and continuing evidence of racial discrimination, even regarding renal transplantation (Ayanian et al. 2004; Callender and Miles 2004) make such a judgment unfair. Why should African Americans assume that this new opt-in system would avoid the unfair practices evident in the rest of the health care system? Thus, we believe that some people may rationally prefer not to opt-in, given the injustices perceived in the current system.

Steinberg recognizes that some rational people hold religious beliefs requiring that they not donate their organs, and that these individuals would thus be unlikely to opt in to the program. Although he notes that “some adjustments should be made to lessen discrimination against potential organ recipients who were unable to join the . . . pool because of established religious views” (Steinberg 2004, 11), he makes no such accounting for fairness in regard to vulnerable populations. We find this oversight troubling. Furthermore, we believe that more than mere adjustments will be required, especially when one recognizes the collection of other groups for whom failing to opt in to the system is far from an irrational choice.

Under the proposed opt-in system, individuals who rationally decline could be punished for their views, by losing priority to people who choose to opt in. This is particularly worrisome for those whose reasons for declining to opt in are related to the belief that they will be unlikely to receive good care if they do. They will be put in double jeopardy: they are less likely to receive equal care as it is (e.g., because of their African-American group membership), and as a consequence of recognizing this fact and taking action to protect themselves (by not opting in), they will be systematically given less preference for receiving needed organs. Ignoring current inequities in the distribution of health

care and the history of oppression in the lives of individuals in this manner punishes the very group of people who have already suffered and are suffering from racial discrimination. Further, even *if* the distrust proved to be irrational or to outlast the realities of unfair treatment (a hypothetical we believe is currently not met), we wonder how a system that burdens those who continue to hold irrational beliefs could be viewed as more just than a system that directly addressed the fears and attempted to build trust.

Other examples of such double jeopardy arise. What happens to individuals who have early-onset organ disease, who may never have the opportunity to opt-in as a healthy person under the proposed system? While the author recognizes the need to make concessions “for children and for adults unable to join the pool because they are not capable of decision making” (Steinberg 2004, 11), some such concession would also have to be made for individuals who retain decisional competency but experience organ failure before they have a reasonable chance to opt in to the donation pool. Otherwise, they would be burdened twice: first when they experience organ failure, and again when they fail to be prioritized.

If we think of the provision of health care and the distribution of organs as a matter of justice, we simply cannot pretend that all individuals and all groups come from similar backgrounds and are equally free to make the choice to opt in as organ donors. Determining what abstract rational individuals would do in an ideal world may be an interesting philosophical exercise, but it cannot provide a suitable foundation for actual practice. Viewing organ distribution as a matter of reciprocal altruism obscures our duty to provide for those who are least able to give back, whether it is due to social oppression or the natural lottery. Justice should not ignore them.

Finally, because we recognize the serious problem of organ scarcity and agree with the author’s concerns about live organ donation, we recommend other possible solutions. First, we agree with Veatch’s recommendation that we should “at least attempt to maximize the convenience of making the donation commitment” before going to other, more radical options (Veatch 2000, 162). For instance, he proposes that we increase the number of sites where one might encounter the opportunity to opt in to the present system (e.g., adding the option to become an organ donor to annual federal income tax returns), and implement “required response” policies at the driver’s license registration centers (so that individuals who fail to answer the organ donor question in some fashion—yes, no, or unsure—will be considered to have an incomplete application; Veatch 2000, 178–179). Second, we recommend community-based education programs designed to reach out to underserved communities to address the distrust of the medical system and the importance of their

participation in organ pools (especially given histocompatibility issues that can be related to race). When such initiatives include cultural sensitivity, full information from reliable sources (including religious and spiritual leaders in many communities of color), and community representation on advisory committees within the health care delivery setting, they have a greater likelihood of success (Callender, Bey and Miles 1994; Miles and Callender 1997). Third, we recommend affirmative action to achieve cultural diversity at all levels of the health profession (Sullivan Commission 2004). In medical education and in practice, more attention should be given to issues of equal treatment and respect for cultural diversity within medicine. Ultimately, we believe that a nondiscriminatory approach for addressing disparities in access to tissue/organs must and can be found (Campanelli 2003). ■

## REFERENCES

- Ayanian, J. Z., P. D. Cleary, J. H. Keogh, S. J. Noonan, J. A. David-Kasdan, and A. M. Epstein. 2004. Physicians' beliefs about racial differences in referral for renal transplantation. *American Journal of Kidney Disorders* 43(2): 386–387.
- Callender, C.O., and P. V. Miles. 2004. Institutionalized racism and end-stage renal disease: Is its impact real or illusionary? *Seminars in Dialysis* 17(3): 177–180.
- Callender, C., A. S. Bey, and P. V. Miles. 1995. A national minority organ/tissue transplant education program: The first step in the evolution of a national minority strategy and minority transplant equity in the USA. *Transplant Proceedings* 27: 1441–1443.
- Callender, C., L. Hall, C. Yeager, A. Washington, and P. G. Smith. 1994. The anatomy of a black community-based transplant education program: A model for community empowerment. In *"It Just Ain't Fair" The Ethics of Health Care for African Americans*, eds. A. Dula and S. Goering, 234–241. Westport, CT: Praeger/Greenwood.
- Campanelli, R. M. 2003. Addressing racial and ethnic disparities. *American Journal of Public Health* 93(10): 1624.
- Dula, A. 1994. African American suspicion of the healthcare system is justified: What do we do about it? *Cambridge Quarterly of Healthcare Ethics* 3(3): 47–57.
- Gamble, V. 1997. Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health* 87(11): 1773–1778.
- Institute of Medicine. 2002. *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academy Press.
- King, P. 1992. The dangers of difference (Twenty years after: The legacy of the Tuskegee syphilis study). *Hastings Center Report* 22(6): 35–38.
- Miles, P., and C. Callender. 1997. Community education and empowerment key to increased minority rates. *Transplant Proceedings* 29:3756–3757.
- Steinberg, D. 2004. An "opting-in" paradigm for kidney transplantation. *The American Journal of Bioethics* 4(4): 4–14.
- Sullivan Commission. 2004. *Missing persons: Minorities in the health professions. A report of the Sullivan Commission on diversity in the health care workforce*. Available from: [www.sullivancommission.org](http://www.sullivancommission.org)
- Thomas, S. B., and S. Crouse Quinn. 1994. The AIDS epidemic and the African-American community: Toward an ethical framework for service delivery. In *"It Just Ain't Fair" The Ethics of Health Care for African Americans*, eds. A. Dula and S. Goering, 75–88. Westport, CT: Praeger/Greenwood.
- Veatch, R. 2000. *Transplantation ethics*. Washington, DC: Georgetown University Press.

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## "Opting-In" and Unnecessary Penalties for Non Kidney Donors

Justin M. List, Institute for Ethics, American Medical Association\*

A variety of systems to procure organs equitably have been theorized or implemented; these include mandated choice, presumed consent, live donors, and volunteer donor registries (Mackey and Kjerulf 2000). In relation to increasing

available kidneys for donation and decreasing use of live kidney donors, Steinberg proposes an "opting in" paradigm that would reward people who agree to donate their kidneys after they die with allocation preference should they need a kidney while they are alive (Steinberg 2004). Although such a system would encourage those who would otherwise donate to do so because of the relative disadvantages associated with not opting in, there are particular disadvantages

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