

Virtual Mentor

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To Donate or Not: Is That the Question?

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A 1993 Gallup Poll found that 85 percent of surveyed participants supported the donation of organs for transplantation [1]. When asked how likely they were to donate their organs upon death, 69 percent of those surveyed said that they were either “somewhat likely” or “very likely” to donate. Ninety-three percent answered that, if asked at the time of death, they would be willing to donate a family member’s organs. One might think that, given the 296 million people living in the United States, these reported percentages would translate into high rates of donation and a relatively short time on an organ waiting list. But this is not the case. As of June 3, 2005, there were 88 165 candidates on the wait list for organ transplantation [2].

The demand for organs continues to increase, and the supply consistently falls short of meeting that demand. Many reasons are given for this gap. For one, many potential donors have not documented their wishes, and family members often decline to donate the organs of their loved one when presented with the option. Some potential donors have deferred donation decisions altogether because of the stress induced by reflection on death and loss [3]. Fears of organ theft, a black market for organs, and physician dereliction of a potential donor in a life-threatening situation may also play into the cultural ethos of organ donation in the US.

The US currently has an opt-in system of informed consent for organ donation operated, in part and most popularly, through the Department of Motor Vehicles (DMV). When obtaining a driver’s license, individuals can indicate that they would like to be donors and select what organs that they would like to donate. Since not all potential donors visit a DMV, information is available—usually upon patient request—at doctor offices and hospitals. Many DMV-declared donors have not discussed their desire to donate with family members, and, even though the license declaration is a legal document, families often override their loved ones’ donation decisions. Physicians and organ procurement organizations (OPOs) do not currently have nationwide legal protections to uphold the wishes of the potential donor against the dissent of a family member [4].

If a majority of Americans indicate that they would donate but actual organ donation rates are lower than would be expected, it follows that increasing the number of documented donors and creating a system that honors donor wishes are crucial challenges confronting OPOs and society at large. Many novel approaches to increasing donation have been proposed in academic and policy literature. To ameliorate the shortage in an innovative way, many authors seek to effectively address common cultural attitudes in America—societal and individual—that impact the

donation decision making process. At the policy implementation level, the problems associated with organ donation are far from solved, prompting many to look to the experiences that other countries have had with organ donation.

Some European and Latin American countries have implemented a presumed-consent model of organ procurement wherein donation is the default policy. Individuals can opt out of this system but it requires that one actively do so. Many of the countries that practice presumed consent, such as Austria and Hungary, have very low opt-out rates, nearing 0 percent of the population [2]. Adoption of presumed-consent policy has been proposed by some groups in the US, but many policymakers and others argue that ingrained US values that favor individual choice over government intervention render presumed consent an inviable option. It should be noted that many of the European countries with presumed-consent policies also have histories of governmental authority over cadavers and autopsies that the US does not. US laws mandate that remains become the responsibility of the next of kin for burial or cremation, a practice not present in some countries [5].

Presumed-consent systems do not completely rectify the problem of organ shortages, but they have dramatically reduced waiting lists in many of the countries where they have been enforced, most notably in Spain [6]. Nonetheless, it is likely that differences in cultural attitudes and political structure mean that the US will need a system that is different from presumed consent to increase organ procurement. Current academic literature contains an abundance of alternatives ranging from awarding “points” for opting in [7] to changing current policies so that they honor patients’ individual donor preferences better.

A mandated-choice model is currently viewed as a potential alternative method for increasing organ supply because its structure reflects the American disposition for choice. Forcing one to choose whether to become documented as either a donor or nondonor is the central feature of this model, which has been promoted as preserving individual choice and increasing the organ supply. Variations of the mandated-choice model might be explored, but pilot studies in Virginia and Texas were not very encouraging—many OPOs and other interested parties who have evaluated the pilot studies found the model less than successful. A sizable proportion of participants—24 percent in Virginia—simply refused to make a decision [8].

About the Virginia experience some researchers concluded, “These data support the hypothesis that many persons who are not opposed to donation still want to leave their family the ‘right to refusal’ and are therefore unwilling to commit to a binding pro-donation decision beforehand” [8]. Some have proposed that when a person fails to make a choice regarding organ donation the default “choice” is in favor of donation. Such a default policy would probably be a contentious facet of a mandated-choice model. Although in theory a mandated-choice policy may best balance individual autonomy with efforts to increase organ supply, as some have argued [9], it has been shown to be fraught with policy difficulties in the experimental models used thus far.

Presumptive consent is a newer idea that is, in essence, a framework for talking with patients and patient's families rather than a donation policy. Presumptive consent is predicated upon 2 ideas—that organ donation is the “right thing to do” and that, given the opportunity to save a life, most people would want to do it [10]. One way that the transplant coordinator can subtly and less directly encourage donation is through value-positive language about organ donation rather than the standard use of value-neutral language. A simple example of positive value, presumptive language is, “When you decide to donate...” compared to, “If you decide to donate...” in the standard model. This approach is seen by some as an easy solution to the organ shortage since it does not require a major external policy overhaul. While it may increase and encourage organ donation, using value-laden language raises ethical questions about coercion—however soft—and trust in the medical encounter.

OPOs, medical professionals, and patients are, by and large, frustrated with the current organ procurement system in the US. In discussing alternative allocation strategies, other factors must be taken into account including personal choice, family relationships, legal protections, and the documentation of decisions. Underneath these factors lies a deeper challenge for advocates of organ donation: better understanding of the intricate psychological facets of human decision making, the influence of language, and deliberate reflections on mortality. The American experience may entail cultural trends unique to its citizens that require specific attention for the purposes of policy making, but, in reality, all organ donor recruitment efforts are likely to require more focus on these complex relationships in order to best understand how to motivate sustained organ donation and awareness.

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