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Professional Arrogance and Public Misunderstanding

Abstract

Any assessment of the impact of required request legislation on organ and tissue procurement must begin by defining required request laws. Of the forty-one states that have passed such laws during the past three years, approximately, half have enacted strong required request policies. These states have mandated that hospital administrators be responsible for insuring that next-of-kin or legal guardians are asked about their willingness to donate organs and tissues of the deceased when a death has been pronounced in a hospital setting.

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- ²⁴ Childress, "Some Moral Connections Between Organ Procurement and Organ Distribution," 93-94.
- ²⁵ See, Department of Health and Human Services, Health Care Financing Administration Proposed Rule, 52 Fed. Register 28666-28677 (July 31, 1987).
- ²⁶ Douglas J. Besharov and Jessica D. Silver, "Rationing Access to Advanced Medical Techniques," *The Journal of Legal Medicine* 8 (November 4, 1987), 507-32.
- ²⁷ Reported in Kaufman and Lynn, 851.
- ²⁸ The End Stage Renal Disease program was intended to be a small part of the Medicare budget when it was added in 1972, with the estimated maximum budget projected at \$100 million. By 1974, the cost was already \$283 million. As of 1986, that program has turned out to be a \$2 billion-a-year undertaking. See Meridith Burke, "Why Not Spend Organ Funds on Other Programs," *Nephrology News and Issues* (March 1987), 8; David A. Ogden, "Organ Procurement and Transplantation," in *Health Care Ethics: A Guide for Decision Makers*, G.R. Anderson and V.A. Glines-Anderson, eds. (Rockville, MD: Aspen Publishers, 1987), 93-94.
- ²⁹ E. Corsini *et al.*, "Cyclosporine A and Transplantation: The Financial Impact," *Dialysis and Transplantation* 15:9 (September 1986), 496-507.
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- ³² See, Fed. Register 52:28666. Although federal legislation supporting transplantation is primarily based on projections of cost effectiveness, the actual cost effectiveness is open to serious question. See Roger W. Evans, "Cost-Effectiveness Analysis of Transplantation," *Surgical Clinics of North America* 66:3 (June 1986), 603-16. Cf. Paul W. Eggers, "Effect of Transplantation on the Medical End-Stage Renal Disease Program," *New England Journal of Medicine* 318:4 (January 28, 1988), 223-29.
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- ³⁶ Michael E. Whitcomb, "Health Care for the Poor: A Public Policy Imperative," *New England Journal of Medicine* 315:19 (November 6, 1986), 1220-22.

³⁷ Burke, "Why Not Spend Organ Funds on Other Programs," p. 9.

³⁸ Caplan, "Requests, Gifts, and Obligations: The Ethics of Organ Procurement," *Transplantation Proceedings* 18:3, Suppl. 2 (June 1986), 49-56; see William E. Parks *et al.*, "Ethical Issues in Transplantation," *Surgical Clinics of North America* 66:3 (June 1986), 635-36.

Professional Arrogance and Public Misunderstanding

by Arthur L. Caplan

Any assessment of the impact of required request legislation on organ and tissue procurement must begin by defining required request laws. Of the forty-one states that have passed such laws during the past three years, approximately half have enacted strong required request policies. These states have mandated that hospital administrators be responsible for insuring that next-of-kin or legal guardians are asked about their willingness to donate organs and tissues of the deceased when a death has been pronounced in a hospital setting.

Most strong required request laws, such as those enacted by Oregon, New York, Massachusetts, and New Jersey, allow a person other than a physician to be designated to make requests. These laws also call for documentation that a request was made and require health departments to facilitate implementation of the legislation by assisting hospitals in educating their staffs and by monitoring the impact of required request legislation on the overall availability of organs and tissues for transplantation. In only one state, Kentucky, is there explicit mention of a penalty for failure to comply with required request legislation.

The federal government and roughly twenty states have enacted laws that differ in important respects from strong required request legislation. Federal law as well as the laws in states such as California and Tennessee mandate that hospitals create protocols through which next-of-kin or legal guardians will

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be notified about the possibility of donating organs or tissues. These "weak" required request laws leave the details of requests and monitoring to individual hospitals. Perhaps the most significant difference, however, is that the federal law, which became effective in November 1987, links the creation of a donor protocol to continued eligibility for receiving monies from the Medicare program.

Because of these substantial variations, assessing the impact of required request legislation is complicated. Moreover, many state laws have been in effect for as little as a year or less. The federal law is simply too new to permit any reliable estimate of its impact on either hospital practices regarding organ and tissue procurement or on the overall availability of organs and tissues for transplantation.

The fact that required request laws have not been enacted in a social policy vacuum makes this task all the more complex. Many states have enacted laws mandating that occupants of automobiles and other vehicles wear seatbelts. Others have raised the legal age for purchasing alcohol and/or stiffened penalties for drunk driving. Still others have lowered the legal maximum speed for vehicular traffic. Since automobile and motorcycle accidents account for a large proportion of those persons whose kidneys, hearts, and other vital organs could be used for transplantation, changes in these laws have a direct impact on the number of persons who die each year who might serve as organ or tissue donors. For example, traffic accident fatalities in Minnesota have declined 10 percent in 1987 from the numbers recorded in 1986. Seat belt laws in Great Britain are believed to have brought about a 15 percent decrease in fatalities from accidents.

Yet no reliable data exist on the actual number of persons who could have donated an organ or a kidney. For all these reasons, it is hard to know exactly how to respond to anecdotal reports concerning the impact of required request on the overall supply of organs and tissues.

My associates and I at the Center for Biomedical Ethics at the University of Minnesota are currently conducting a telephone survey of ten states in which required request laws of one kind or another have been in effect for more than six months. We have contacted organ procurement agencies, health department officials, and representatives of regional eyebanks to obtain whatever information they can offer concerning the impact of the new laws.

None of the ten states, including many with policies of mandatory reporting to health departments, has compiled reliable figures on the number of vital organs or tissues available before and after the enactment of required request legislation. However, those surveyed do report several trends

and problems with required request that shed some light on the impact of state laws.

Tissue donation, including corneas, skin, bone, dural tissues, and tendons, has increased dramatically since the enactment of required request laws. Increases on the order of 200 to 300 percent are common. While impressive, these numbers ought to be even greater given the large number of persons who could donate tissue upon their deaths.

Organ donation has increased from 10 to 20 percent in many states. In others there has been no increase over the numbers of vital organs available for transplant prior to required request laws. The fact that organ donation has remained constant despite significant decreases in traffic fatalities provides some evidence that the laws have had a small positive impact on the supply of organs available for transplantation.

The primary problem cited by organ procurement officials, eyebank representatives, and health department officials has been the inadequacy of educational efforts directed toward health care professionals. As one organ procurement official observed, "if you simply ask relatives about organ donation by citing the law the consent rate is zero." No state has provided even a minimally adequate level of professional education to those who bear the obligation of making requests for organ donation. Whether physicians, nurses, or others, those responsible for asking need training in making these exceedingly emotion-laden requests.

The other major obstacle noted by the majority of procurement officials and state health department representatives is resistance by physicians to complying with the new laws. Rates of compliance in many states do not exceed 50 percent. Physician noncompliance appears to be primarily a result of the resentment held by physicians against nonphysicians, most specifically legislators and bureaucrats, about being told what they *must* do. As several health department officials commented, physicians are not comfortable requesting organ donation from family members and are even less comfortable when confronted by yet another governmental attempt to regulate the practice of medicine.

One might interpret the problem of physician noncompliance with required request laws, be they strong or weak, as evidence supporting Martyn, Wright, and Clark's position concerning moral, clinical, and legal problems with required request legislation. While physicians often do not want to ask about organ donation, whether the law requires it or not, very little in the arguments presented by Martyn, Wright, and Clark about ethical problems with required request is persuasive.

Their critique of required request legislation is

prompted by what turns out to be, on closer examination, several inaccuracies. The authors maintain that "institutionalizing the identification of potential organ donors appears to assume a shift in the physician's clinical attitude so that willingness to diagnose or even hasten the diagnosis of brain death supersedes the incentive to fight for life." It is hard to imagine a claim about required request that could be farther from the truth.

In general, both strong and weak versions of required request laws were enacted as amendments to existing Uniform Anatomical Gift legislation. Strong required request laws are quite specific about the fact that no requests are to be made until death has been pronounced. Such versions of the law do nothing to alter a physician's traditional obligation to provide care as long as the patient can possibly benefit. Weak required request laws allow individual hospitals complete discretion as to the nature of their protocols for notifying family members of the option of donation. In neither situation are the standard requirements for separating the roles of those who provide treatment and those who pronounce death in any way altered or weakened.

Moreover, the legal climate pervading American medicine is hardly conducive to efforts to hasten death or fudge a brain death diagnosis to obtain an organ or tissue donor, particularly given the fact that potential recipients are either unknown or nearly always awaiting an organ at a different hospital. Physicians have little economic or psychological motivation to become involved in time-consuming and resource-intensive efforts to recover organs or tissues when the beneficiaries of their efforts are likely to be transplant teams and their patients at other hospitals in other states. It is, therefore, ludicrous to argue that doctors will be compelled by required request legislation to kill or murder helpless patients when many of them find organ procurement a nuisance simply on the grounds of professional autonomy or the absence of adequate fiscal or psychological rewards.

The authors also suggest that required request legislation is morally suspect in that it encourages dehumanization of the dead, who come to be viewed only as portable organ and tissue banks. There is not a smidgen of empirical evidence, anecdotal or otherwise, mustered in support of this thesis. In addition, if this claim were true, it would stand as a convincing argument against all forms of organ procurement, whether inspired by required request legislation or any other public policy. If health care professionals are actually put in an untenable moral bind due to a genuine "conflict between encouraging hope (through caregiving) and causing the family to lose hope (through the donation request)," then

In enacting required request legislation, our society has indicated its collective desire that people routinely be given the option of organ and tissue donation as a last act of respect for the dead and their families and as an expression of concern for those who will die unless more organs and tissues are made available.

no form of organ request is ethically acceptable.

Similarly, assertions about physician insensitivity to families' needs "to express feelings about the relationship now lost [as a result of the death of a loved one]" impugn all forms of soliciting organs and tissues no matter how tolerant they may be of professional hesitation about making requests. The authors fail to perceive that required request will more likely enable families to make informed choices about organ donation. The requirement of a request will allow those who are living to anticipate the request in advance of a tragedy and make their wishes known to family members. The routinization of requests by properly educated health care personnel enhances the likelihood of autonomous choice over the haphazard sorts of inquiries that preceded the enactment of required request legislation.

Further, there is absolutely no evidence to warrant the authors' view that families "reconstruct the events surrounding a death in the weeks, months, and years that follow" and "feel that organ donation involved treating their loved one as object not subject." The anecdotal evidence that does exist supports a quite different conclusion.

Organ procurement personnel have repeatedly indicated that many families express regret weeks, months, and even years later at not having considered the option of organ donation, not having acted on the stated wishes of their deceased loved one to donate, or having refused a request for donation. What donor families do desire is to know what happened as a result of the donation. Often such follow-up information is not provided in a timely manner to donor families.

The final inaccuracy is a true howler. Martyn, Wright, and Clark maintain that in other countries required request laws "were the first step toward presumed consent laws." Required request laws are portrayed as the "edge of the wedge" by which

voluntarism and altruism will be replaced by the totalitarianism of state mandated beneficence. This is sheer nonsense.

None of the fifteen nations that have presumed consent laws (including most recently Singapore, which enacted such a law in the fall of 1987) have previously had any form of required request legislation. Prior to 1986, the United States was the only nation to have enacted or even debated a required request law. While one Canadian province has enacted required request legislation and some other nations, such as the United Kingdom and The Netherlands, are considering proposals, no nation has moved from a policy of requiring requests to taking organs and tissues by legislative fiat.

Required request laws emerged as a distinct alternative to, not a preamble for, presumed consent. Indeed, many who favored presumed consent laws for the United States viewed required request as a step backward rather than as a first step on the road to their desired public policy objective. Whatever the ethical case for presumed consent laws, required request as a public policy approach consciously reflects a sensitivity to the key values of voluntarism, altruism, and informed choice that have formed the core of American moral and legal thinking about organ and tissue procurement since the creation of the Uniform Anatomical Gift Act in 1968.

The most persuasive argument that Martyn, Wright, and Clark are able to muster against required request legislation is that if the laws are effective they will have adverse fiscal consequences. Transplants are expensive and if they are financed by public funds there will be less money available to meet the legitimate health care needs of others.

But is the cost of having a greater supply of organs and tissues available for transplant really a reason not to try and obtain organs and tissues? Should the answer to such a question hinge on cost, or, rather, on the steps needed to assure access to efficacious medical care for all Americans with medical needs?

If overall expenditure is the standard by which our moral obligation to those with terminal illness is to be measured then many other Americans will have to yield their access to medical care to others. Those with AIDS, terminal cancers, head injuries, spinal cord injuries, and severe congenital anomalies impose a far greater burden on the national treasury than anything organ and tissue transplants could pose under even the most optimistic scenarios concerning required request. Surely the correct ethical answer to public policy regarding organ and tissue procurement is to seek ways to reduce the costs of transplants rather than to ignore the fact that thousands of Americans die or remain severely

disabled simply for want of an organ or tissue donor.

Martyn, Wright, and Clark conclude their critique of required request with a call for a redirection of efforts to educate the American public about organ and tissue donation. Public education is surely commendable, but it has little to do with the primary difficulties confronting required request laws. The major problems are the unavailability of data on the size of the pool of organ and tissue donors, the failure of states and the federal government to support legislation with adequate professional education, and the failure of the transplant community to address the audience most in need of education and persuasion where matters of organ and tissue donation are concerned—health care professionals.

The transplant community has taken great solace over the years in the view that the public's lack of awareness and understanding of organ and tissue donation is the primary obstacle to broader support for organ procurement. But if opinion surveys are to be believed, the public knows full well about the need for transplants.

The public continues to evince a strong interest in organ and tissue donation although that interest has declined somewhat in recent years. This may result from a sudden onslaught of ignorance but, I believe that rather than moral callousness on the part of the citizenry, other factors are responsible, factors far more disquieting to the transplant community.

It is health care professionals, not the general public, who are in desperate need of education about their duties where organ and tissue procurement is concerned. They need to be taught how to make requests, or, if they are too discomfited by death, to yield authority over matters pertaining to procurement to others more adept at dealing with this harsh reality.

In enacting required request legislation, our society has indicated its collective desire that people routinely be given the option of organ and tissue donation as a last act of respect for the dead and their families and as an expression of concern for those who will die unless more organs and tissues are made available. It has not yet put its money where its ethical concerns are in the form of resources to train health care professionals to feel comfortable rather than angry in discharging their obligations to the dead and those who are dying. Until these resources are forthcoming and directed to the audience of health care professionals where they are most needed, the ethical, clinical, and legal impact of required request will remain unknown.