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Organ Procurement, Values and Public Policy

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ABSTRACT — The success of organ transplants in recent years has created a shortage of transplantable cadaver organs. Voluntarism, the primary mode of organ procurement currently in use nationwide, appears to be no longer successful. Policymakers and others are examining alternatives to the current system, namely, presumed consent (routine salvaging) and required request. In this process, there is a danger in considering only the effectiveness of the means and neglecting the value and belief commitments that underlie them. These need to be brought to the surface because they ultimately contribute toward shaping the moral character of society. In this light, required request might be a preferable public policy option because it balances the values of voluntarism (autonomy, individual rights, and charity) with those of presumed consent (community, social well-being, and justice). It also promises to be more effective than either of the other two alternatives.

Introduction

Organ transplantation is a phenomenon of just a little more than a quarter century. In the 36 years since Dr. David Hume of Boston performed the first modern kidney transplant using a cadaver organ, transplantation has become a procedure more frequently employed and increasingly successful. This has been due to important advances in recent years, namely, greater sophistication in surgical techniques, better methods of tissue typing, and the discovery of new immunosuppressive drugs such as cyclosporin. The latter has greatly increased the survival rate of transplant recipients.

This success, however, is not without its problems. Chief among them is the procurement of transplantable organs. Not only is there an existing gap between the need for organs and the available supply, but this gap is rapidly widening. Recent studies indicate that in 1982 there were only 2,500 organ donors in this country out of 20,000 potential candidates — young to middle-aged persons who have suffered brain death as the result of accident, drowning, gunshots to the head, and viral infection among other causes. Hence, only about 15% of the possible pool of donors make provisions for the use of their organs (1). Meanwhile, hundreds of people die each year awaiting transplants, and thousands of others do not receive the transplants that would greatly enhance their quality of life.

The procurement of additional organs poses a serious and urgent public policy issue. The current mechanism for obtaining transplantable organs, known as "voluntarism," was developed in the early days of transplantation and no longer appears to be effective. A number of alternatives — presumed consent and required request — have been and are continuing to be considered by policymakers, health care providers, ethicists, and others. One of these, "required request," will probably come up before the 1987 Minnesota legislature. Several states — California, Oregon, and New York among them — have already opted for this approach. If more and

more states follow suit, a new public policy for the procurement of cadaver organs will have emerged.

In considering which procedure to pursue, lawmakers and other participants in the debate need to realize that the issue in question is not only one of efficiency and effectiveness. The only concern is not and cannot be increasing the number of organs for transplant, though this would certainly appear to be the sole or, if not the sole, at least the dominant issue. In the humanitarian concern to save and improve life and in the fascination with and confidence in such technological developments, society could be swept away by a pragmatic concern for what works. Policy shapers at all levels could neglect the larger and more nebulous questions of meaning and how choices about what to do shape the kinds of persons and the kinds of communities that individuals and societies become. Achievements in medicine challenge society not only technologically, but also humanly. The choices to be made are not only about technological progress, but also about human development.

This is so because underlying the procedural considerations in the retrieval of organs are considerations about basic values such as autonomy, justice, and charity as well as some basic beliefs about the relation of the individual to society, the treatment of the newly dead, the importance of the human body, the responsibilities of family members for a deceased individual, the obligation to save life and to pursue technological progress. Implicitly or explicitly, these factors are an intrinsic part of public policy choices in the matter of organ procurement.

There are at least two levels, therefore, to decisions about how to increase the supply of cadaver organs — the practical level dealing with the most effective mechanism, and the theoretical or meaning level dealing with the values and beliefs that society commits itself to in opting for a particular procedure. Both are the concern of this paper. I intend to examine the three dominant policy options — voluntarism, presumed consent, and required request — in terms of 1) their workability and effectiveness, and 2) the underlying assumptions of each, and attempt to argue for the preferability of required request at both levels.

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Social Policy Options for Organ Procurement

Voluntarism

As previously noted, the primary mode of organ retrieval presently in use nationwide is "voluntarism." This procedure consists in an individual's making provision while alive for the donation of one or more organs if and when brain-death has been determined, or a family's giving consent for donation in the absence of such provision. In the first case, the prospective donor's decision is communicated either through a donor card, or by an appropriate indication on a driver's license, or both. In the latter case, next of kin may either come forward to donate organs or be approached by hospital personnel to do so.

This mechanism emerged in the late 1960s, the early days of organ transplantation. Once cornea transplants began to be performed in the 1950s, states found it necessary to enact legislation providing for the possibility of individuals donating all or part of their bodies to medicine. By 1965, most states had some legal provision in place, but these differed from state to state. Some had no mechanism whatsoever. In the interests of uniformity, the National Conference of Commissioners on Uniform State Laws drafted the Uniform Anatomical Gift Act (UAGA) in 1968. It was adopted by all states and the District of Columbia by 1971.

The Act, based on individual freedom and autonomous choice, contained several provisions (2). The two major ones — personal voluntary donation and next-of-kin donation — were noted above. In addition, the Act recognized a donor card as a valid legal document when witnessed by two people. This, in effect, means that the wishes of the decedent take precedence over those of the family, and that health care personnel who comply with it are not subject to litigation. In those cases where the decedent has expressed no intentions, the Act established a clear order of priority for next-of-kin consent as well as a mechanism for obtaining that consent (a written message, telegram, or recorded telephone message).

This method of organ procurement seems not to be working. Critics offer several explanations (1, 3). First, the majority of Americans have not indicated their wishes regarding organ donation. This does not seem to indicate a reluctance to donate (a 1983 Gallup poll found that 70% of Americans are willing) as much as it does a lack of initiative in taking the appropriate steps, or a lack of awareness about how to do so. The majority of the population never comes into contact with the donor card. It is estimated that only 20% of the population have signed cards and only 3% are carrying them at the time they are pronounced brain dead. States differ in how they use the driver's license for organ donation. Some provide a check-off box, others stamp "organ donor" on the license, and yet others attach donor cards to the licenses. In any case, no state has more than a 20% positive indication.

Second, even though an individual may have signed a donor card or have made the appropriate indication on a driver's license, the donor card and/or license might not be sought or found by medical personnel. Medical personnel, in turn, might or might not inquire of next of kin whether this particular individual is known to be an organ donor. Here the fault lies with health care providers. Some may simply lack initiative, or interest in organ transplantation, while others may be inadvertent to the opportunity for retrieving organs or the mechanisms for doing so, while yet others may recoil from the situation for psychological reasons (4) or because of discomfort in approaching family at a time of extreme crisis.

Third, even though it may be clear that an individual is an organ donor, hospital personnel will almost always request

permission from the next of kin, even though this is unnecessary according to the UAGA. Physicians and nurses do this to respect the family's quasi-property rights over the body and their wishes regarding donation, as well as to avoid bad publicity and the possibility of future litigation. Rarely if ever are family wishes overturned even though they might contradict the previously expressed desires of the decedent. Hence, in effect, donor cards serve only to sensitize people to the possibility of organ donation and to convey to families the wishes of a now deceased member.

These are the pragmatic procedural considerations. They deal with what does or does not work. But what are the value questions associated with voluntarism? What are the assumptions and convictions underlying this particular public policy option?

Blair and Alfred Sadler, Jr., very strong proponents of voluntarism, argue that the current system strikes a balance between individual values and rights, and the possibility of donating and obtaining organs (5, 6). That is to say, it provides a mode of organ procurement while at the same time respects individual freedom of choice, freedom of religion, and the right to privacy, as well as the personal and aesthetic interests of the family, and encourages public support for and involvement in transplantation efforts. Voluntarism allows the individual to decide about the disposition of his or her body after death and protects the family's quasi-property rights over the body. Equally, if not more important, it maintains the "gift" character of organ donation.

Another advocate of voluntarism, Paul Ramsey, proposed two reasons for what he called "organized giving" in his 1970 book, *The Patient As Person* (7). The first centers on people's religious or nonreligious convictions about the body that might incline them to not want to donate. These individuals should not have to fight a system that might infringe on these beliefs and choices in a time of crisis. The second and perhaps more important reason is the impact of "giving" rather than "taking" upon the human community. A routine taking of organs not only would deprive individuals of an opportunity to exercise the virtue of generosity, it would also not contribute to the fostering and strengthening of "consensual community." According to Ramsey, responding to the need for gifts by giving has a civilizing effect and "meets the measure of authentic community." In effect, he cautions against a utilitarian mentality in the service of medical progress and even saving lives that fails to recognize other crucial and even more basic considerations.

William E. May, a Protestant ethicist, in many respects echoes Ramsey's views (8). He too believes that voluntarism is an expression of "self-donative love," a form of "assistance that one mortal renders another," and that such giving will have a positive influence on the quality of the community. He is also concerned about the body. For May, the corpse should enjoy a kind of "extra-territoriality," that is to say, it does not belong without limit to society. The state does not have an unlimited claim upon the person whether living or dead. In fact, traditionally, society has recognized "quasi-property rights" to the corpse in the next of kin. While these property rights do not extend to a commercial use of the corpse, they do allow the family to possess the body and to carry out its right and obligation to attend to the corpse's disposition. Normally, no other entity can put claims upon the body that would interfere with this right. And, certainly, the family should not have to claim the body as its possession. Such would seem to be the case with a policy of routine salvaging of organs.

Advocates of voluntarism, therefore, in addition to their

belief that it is an adequate mechanism, also see it as upholding the "gift" character of organ donation, as a schooling in the virtue of generosity, as an affirmation of individual free choice and particular rights, and as a protection against an excessive claim of the state upon the individual. They tend to come down on the side of individualism.

Presumed Consent

A second public policy alternative for the retrieval of transplantable organs is what is known as "presumed consent" or "routine salvaging." It has been proposed by a number of individuals for adoption in the United States in place of the current system. Presumed consent is now employed in a number of European nations including Austria, Denmark, France, Italy, Israel, Poland, Norway, Spain, Sweden, and Switzerland.

Under presumed consent, it is *assumed* that individuals are in fact willing to donate their organs when death has been determined. Given appropriate circumstances (brain death, proper age, healthy organs, etc.), organs and tissues will routinely be harvested unless there has been a prior objection registered either by the individual or by next of kin. Hence, the burden here is shifted from the medical personnel to obtain consent to the individual or family to refuse it. In the absence of objections, the individual is considered a potential donor (9).

Indications are that presumed consent has not been particularly effective in resolving the shortage of transplantable organs in those countries in which it is being employed. In part, this seems to be due to the fact that physicians in these countries do not remove organs without the prior consent of next of kin even though this is not legally required. Some families refuse, while in other cases physicians are reluctant to approach family members at all with the request. Supporters of this alternative argue that were it to be employed as it should be, it would be effective.

Why a policy of presumed consent, beyond the practical hope that it will ameliorate the shortage of organs for transplant?

In a recent article, Kevin O'Rourke and Philip Boyle argue for presumed consent on the basis of justice, more specifically, legal or general justice (10, 11). As members of a community, citizens have an obligation in justice to contribute to the good of the community. Because the life and health of individuals contribute to the overall well-being of the society, O'Rourke and Boyle argue that there is some obligation in justice to be willing to give one's organs after death. Community interests in this proposal would seem to take some priority over individual and familial interests and rights.

Arthur Caplan, recently appointed Director of the Center for Bioethics at the University of Minnesota, though he himself does not espouse presumed consent, does suggest a possible further justification in the principle of beneficence (3). In contrast to the principle of nonmaleficence which requires that harm not be done to others, beneficence means that we ought to do good to others. The question arises in the application of this principle: How much good does one have a duty to perform? Are there limits to what one must do for another? These types of questions have normally been answered in this way. People have a duty to benefit others when the expected benefit is significant, when it is likely to occur, and when it is of little or no risk or harm to the individual. In the case of organ donation, there is no suffering, pain, or harm for the deceased. Significant benefit will come to the recipient, and there is a high likelihood of its coming about. Therefore, some would suggest that there is even a moral duty to donate one's

organs. Routine harvesting simply assumes that one would want to fulfill one's duty to others who are in need, who can benefit. A life can be saved or the living of a life can be improved at no cost to the donor.

Why do the critics of presumed consent oppose it? We return here to Ramsey and May. Neither sees this particular option to be ethically unacceptable. Rather they view it as undesirable at the level of underlying meanings.

Ramsey laments the shift from "giving" to "taking." One can no longer speak of organ "donation" because the "giving" of organs would really result from a failure to positively refuse the gift. Furthermore, presumed consent violates the "sacred trust" of the family for the body of the deceased expressed in the quasi-property rights discussed above. What social interests override this sacred trust? Is the need for organs to be included with other exceptions such as autopsies in criminal investigations or in cases of communicable disease? These quasi-property rights, according to Ramsey, are based not only on positive law, but on a deeper sense of "familial duties and sacred trusts arising out of our common humanity."

May is likeminded in this critique of routine salvaging. He raises two objections. First, he notes that many people have an aversion to the notion of routine salvaging, an aversion that should not be ignored even for laudable goals. He does not believe that perceptions of social need should override all other considerations or that the means for obtaining organs should become "everyday, routine, and casual." Second, May is concerned about the possible impact of this mechanism upon society's image of the hospital. What has traditionally been perceived as a place of healing and recuperation could, with routine harvesting, be seen as a "devourer." In the hospital, one's very vitals are devoured by the state on behalf of the social order. The consumption that dominates society is now consummated in the health care institution. All of this could weaken the trust that is the basis of the healing art.

Two other objections have been raised to presumed consent, but in its more extreme form, sometimes called "strong presumed consent." Here, organs are routinely retrieved regardless of objections to the contrary. Such a policy according to Blair and Alfred Sadler, raises constitutional issues. It would seem, in the first place, to violate the First Amendment to the Constitution if it prevented a person who believed that his faith required him to be buried intact from freely exercising this religious belief. Those justifying this approach would need to show that there was both an overriding public need for organs and no other way to obtain an adequate supply. In the second place, there might also be possibility of a violation of the 14th Amendment in depriving an individual or next of kin control over disposition of the corpse after death, a possible violation of due process. Again, overriding this right would depend on there being a lifesaving need and no other alternatives.

Required Request

There is yet a third possible policy option for the procurement of organs. It has been termed "required request" by Arthur Caplan, who is one of its major proponents (3).

Under required request, a properly trained hospital representative would be obliged to approach the family of all potential donors at the time of death. In those cases where an individual has signed a donor card or has some other written designation of intent, this system would ensure that medical personnel or next of kin attempt to locate it. If there is no such indication, and for the majority of Americans there probably would not be, then family would have to be asked for permission to retrieve organs.

Clearly, responsibility for obtaining organs is placed upon hospital personnel. In order to ensure compliance with a required request statute, a form would need to be completed in each case ascertaining that the request had been made, and this form would later be attached to the death certificate. A required request statute, which ideally would be enacted in every state, would allow for exceptions if it were believed that approaching a particular family would be harmful to them. This, too, would have to be put in writing.

Why this approach? In the first place, it respects the autonomy of the individual and of the family, as well as the quasi property rights of the latter. Furthermore, since it is the next of kin who have responsibility for the disposition of the body, it would not seem to be an undue burden to inquire of them about a use of the body prior to disposition. Secondly, it involves next of kin in the process of organ procurement. Although the circumstances in which the request is made are stressful, most families will consent when asked and most will find it therapeutic. Thirdly, this mechanism maintains the "gift" character of donation and, by not making procurement routine, it protects somewhat against developing a "spare-parts" mentality. Fourthly, it seems to recognize a mild duty in justice to make the gift of one's organs. While it does not require this exercise of justice, it does seem to imply that donating one's organs for the good of society is perhaps something that one should do, and so next of kin will be asked to do so. Fifthly, it places the burden of organ procurement on the medical profession where it in fact belongs. If transplantors and transplant programs wish more cadaver organs, it is they who should take the initiative to obtain them.

If it is the case that the majority of people in this country are willing to be donors but no one bothers to ask them to donate, then required request seems to make some sense. The drawback, of course, is in approaching family members in a time of extreme crisis. However, a policy of required request, if sufficiently publicized and accompanied by educational strategies, could generate discussion of organ donation among family members, allowing for personal wishes to be known, and create the expectation that requests will be made in cases of brain death. To some degree this might reduce the element of surprise, awkwardness, and stress. Required request has been successful where it has been employed.

Conclusion

Three public policy options for the procurement of transplantable organs and tissues have been considered as a possible means for resolving or at least alleviating the current shortage. Each has much to be said for and against it. If one were to consider only the end result — an increase in the number of available organs — one might be inclined to opt for a form of compulsory retrieval. However, if one takes account of the value dimensions of that alternative, it would become relatively clear that it tends toward a communitarian, even a utilitarian, emphasis. Such a direction is not without its problems, particularly when the major issues in medical ethics are becoming less individually focused and more socially focused. In pursuing the good of society as a whole or the good of the greatest number, there is danger of riding roughshod over the individual. In the extreme, this approach will sacrifice the one for the good of the whole or the many. Opting for presumed consent nationwide may appear to be of minor significance in the much broader picture of bioethical choices and policies, and of even less significance in the whole range of societal decisions. But society's commitment

to this mechanism would also be a commitment to certain values and beliefs. It would be part of a pattern that shapes the kind of people we are and become.

On the other hand, voluntarism tends perhaps too much to the side of individualism. Ours is an age of individualism, an individualism that frequently takes the form of an assertion of personal rights that actually translates into the pursuit of one's interests and desires unhindered. One of the dangers here, as Robert Bellah points out in *Habits of the Heart* (12), is a forgetfulness of community, a loss of the sense of the common good and of our responsibilities as members of society to contribute to the well-being of the whole. The emphasis on freedom, autonomy, self-determination, and individual rights, taken to excess, can undermine social life.

Both presumed consent and voluntarism reflect and promote crucial, though different, values and beliefs. It may be that required request, at least to some degree, blends and balances the commitments inherent in the other two alternatives. It respects individual autonomy and rights while working toward the good of society. It promotes free giving, while perhaps suggesting a mild duty in justice to meet the need of others by giving one's organs. For this reason, it may be a preferable public policy option.

There is undoubtedly good reason to be concerned about the need for transplantable organs, but there is also good reason to be at least as concerned about the means employed in obtaining them. As Willard Gaylin, president of the Hastings Center, has said so well: "Sustaining life is an urgent argument for any measure, but not if that measure destroys those very qualities that make life worth sustaining." (13).

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