

6.1.4 Presumed Consent & Mandated Choice for Organs from Deceased Donors

Organ transplantation offers hope for patients suffering end-stage organ failure. However, the supply of organs for transplantation is inadequate to meet the clinical need. Proposals to increase donation have included studying possible financial incentives for donation and changing the approach to consent for cadaveric donation through “presumed consent” and “mandated choice.”

Both presumed consent and mandated choice models contrast with the prevailing traditional model of voluntary consent to donation, in which prospective donors indicate their preferences, but the models raise distinct ethical concerns. Under presumed consent, deceased individuals are presumed to be organ donors unless they have indicated their refusal to donate. Donations under presumed consent would be ethically appropriate only if it could be determined that individuals were aware of the presumption that they were willing to donate organs and if effective and easily accessible mechanisms for documenting and honoring refusals to donate had been established. Physicians could proceed with organ procurement based on presumed consent only after verifying that there was no documented prior refusal and that the family was not aware of any objection to donation by the deceased.

Under mandated choice, individuals are required to express their preferences regarding donation at the time they execute a state-regulated task. Donations under mandated choice would be ethically appropriate only if an individual’s choice was made on the basis of a meaningful exchange of information about organ donation in keeping with the principles of informed consent. Physicians could proceed with organ procurement based on mandated choice only after verifying that the individual’s consent to donate was documented.

These models merit further study to determine whether either or both can be implemented in a way that meets fundamental ethical criteria for informed consent and provides clear evidence that their benefits outweigh ethical concerns.

Physicians who propose to develop or participate in pilot studies of presumed consent or mandated choice should ensure that the study adheres to the following guidelines:

- (a) Is scientifically well designed and defines clear, measurable outcomes in a written protocol.
- (b) Has been developed in consultation with the population among whom it is to be carried out.
- (c) Has been reviewed and approved by an appropriate oversight body and is carried out in keeping with guidelines for ethical research.

Unless there are data that suggest a positive effect on donation, neither presumed consent nor mandated choice for cadaveric organ donation should be widely implemented.

AMA Principles of Medical Ethics: I,III,V

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 7-A-05 Presumed consent for organ donation

CEJA Report 2-I-93 Strategies for cadaveric organ procurement: mandated choice and presumed consent

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 7 - A-05

Subject: Presumed Consent for Organ Donation
(Resolution 2, A-04)

Presented by: Michael S. Goldrich, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Art L. Klawitter, MD, Chair)

1 At the 2004 Annual Meeting of the House of Delegates, Resolution 2, “Presumed Consent for
2 Organ Donation,” introduced by the Pennsylvania Delegation, called for the American Medical
3 Association to “support presumed consent for organ donation as a means of increasing the number
4 of organs available for transplantation” and to “pursue national implementation of such a policy.”
5 This resolution was referred to the Board of Trustees, and assigned to the Council on Ethical and
6 Judicial Affairs for report back to the House of Delegates in June 2005.

7 8 BACKGROUND

9
10 Since the introduction of organ transplantation in the 1950s, the number of individuals who could
11 benefit from this procedure continually has outstripped the number of available donor organs.
12 Despite ongoing efforts to address unmet needs, the disparity has increased with time. Developing
13 strategies to increase organ donation remains a priority for the transplant field and the medical
14 profession; innovative approaches always are being considered.

15
16 One approach that has received attention over the last several decades involves changing the
17 standard of consent for donation from deceased donors. Currently, organ procurement in the
18 United States is structured around an opt-in system of informed consent: individuals with adequate
19 decision-making capacity are regarded as voluntary donors if they expressly have indicated their
20 willingness to donate. In the absence of explicit consent from a potential donor, the next-of-kin
21 generally are granted the authority to determine whether organs may be donated.

22
23 Since 1968, the proposal to implement a system of presumed consent for organ donation has been
24 debated.¹ Under such a model, individuals’ willingness to donate would be assumed unless they
25 specifically opted out by withdrawing their consent. Under some variations, absent registered
26 objections to donate by the decedent, families still would be notified at the time of death that
27 organs were going to be removed, offering a final opportunity to communicate known objections.

28
29 Presumed consent, which supporters believe would help increase deceased donation substantially,
30 has been implemented in some European and South American countries. Some studies seem to

* Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 validate the effectiveness of a presumed consent model in those countries.² Other findings,
2 however, indicate that presumed consent has resulted in only a modest increase of transplantable
3 organs.^{3,4} Moreover, it is not known whether presumed consent would be accepted as readily in
4 the United States, set apart by our distinct culture of pluralism, individualism, and self-
5 determination.⁵

6
7 **OPINION E-2.155, "MANDATED CHOICE AND PRESUMED CONSENT FOR CADAVERIC**
8 **ORGAN DONATION"**

9
10 Since 1994, the Council on Ethical and Judicial Affairs has had a policy that addresses presumed
11 consent for deceased donation. Opinion E-2.155, "Mandated Choice and Presumed Consent for
12 Cadaveric Organ Donation," (AMA Policy Database) states that "a system of presumed consent for
13 organ donation, in which individuals are assumed to consent to be organ donors after death unless
14 they indicate their refusal to consent, raises serious ethical concerns."⁶ Instead, the policy
15 recommends a system of mandated choice as an ethically appropriate way to encourage donation.⁶
16

17 In the Opinion, the lack of an effective mechanism to document individuals' decisions to withdraw
18 consent is identified as a significant barrier to adopting a presumed consent model.⁶ While solving
19 this shortcoming may be surmountable, it is worth noting the limited success of attempts in our
20 current system at documenting individuals' donation preferences in a systematic fashion.
21 Moreover, even an operational registry would be useful only if all members of the public were
22 aware of the policy of presumed consent and had easy access to the registry. At present, for
23 example, most states depend on their Departments of Motor Vehicles (DMV) to make contact with
24 citizens regarding organ donation. However, DMVs do not reach all individuals, because many
25 adults do not hold a driving license or other state identification card. Even for those who access the
26 DMV, the setting is less than optimal to provide information regarding donation.
27

28 In the report that served as the basis for the Opinion E-2.155, several additional concerns were
29 identified.⁷ Among them were the possibility that relying on presumed consent might remove an
30 incentive for physicians to initiate discussion of organ donation with their patients.⁷ Moreover,
31 individuals reluctant to think about death and dying might avoid reflecting on their attitudes toward
32 donation and be wrongly assumed to be willing donors.⁷
33

34 In lieu of a presumed consent model, the Opinion recommended a mandated choice system,
35 whereby individuals are required to express their preferences regarding organ donation.⁶ Mandated
36 choice may prove effective in increasing number of donations for several reasons. It reduces the
37 stress of asking grieving families to decide whether an individual would have chosen to donate and
38 it enables a time sensitive process to advance faster. Under mandated choice, there is greater
39 assurance than under presumed consent that individuals' autonomy will be protected, because they
40 specifically would have made known their wishes concerning organ donation.
41

42 **ADDITIONAL CONSIDERATIONS REGARDING PRESUMED CONSENT AND**
43 **MANDATED CHOICE**

44
45 A review of the recent literature reveals that both presumed consent and mandated choice have
46 repeatedly been considered as strategies that might help increase the number of deceased
47 donations. Given the finding that most people are supportive of donation but fail to act on their
48 intentions, both systems could substantially increase the donor pool.⁸ Either system, then, might
49 prevent some deaths and relieve the suffering that results from organ failure.⁹

1 *Presumed Consent*

2

3 Many have argued in favor of presumed consent.⁹⁻¹¹ Along with the reasons already cited in this
4 report, the claim has been made that presumed consent would better protect individuals' autonomy
5 than the current system. Indeed, the current system tends to rely not on the preferences of the
6 decedent, but on those of their surviving family members,⁹ and assumes that the absence of express
7 consent indicates a refusal to donate. Yet, this assumption is not corroborated by surveys that find
8 most members of society favor donation.

9

10 Presumed consent also might increase the number of deceased donors simply because many people
11 would avoid having to make an active decision on a topic that can be difficult and stressful to
12 contemplate.² For this reason, presumed consent is seen by some as an affront to individuals' right
13 to make decisions and to exercise self-determination.^{5, 12} The presumed consent model may also be
14 perceived as culturally or religiously insensitive.

15

16 The assumption that individuals will be proactive in considering their options under a presumed
17 consent system is doubted by many, even when members of a community are aware that presumed
18 consent is the accepted standard and know of easily accessible and effective mechanisms to register
19 withdrawal of consent. There is also concern that presumed consent ultimately could contribute to
20 distrust of the health care system and the medical profession, causing some individuals, previously
21 inclined to donate, to document their refusal.¹³

22

23 *Mandated Choice*

24

25 Generally, mandated choice seems to avoid the limitations both of a presumed consent model,
26 which relies on the assumption that people are aware of the system and that their inaction reflects
27 an inclination to donate, and of our current system, which allows people to remain apathetic. By
28 requiring all people to consider whether they would agree to donation, mandated choice can help
29 ensure that their preferences will be known and respected. Thus, mandated choice has the potential
30 to promote individual autonomy, while also helping to increase the number of deceased donors.

31

32 Mandated choice has been criticized, however, on a number of grounds, including the requirement
33 for individuals to make a decision, whether they want to or not. Because individuals *must* choose,
34 a default option must be in place for those who decline to make a decision, either presuming
35 consent, with its attendant problems as noted above, or presuming refusal, which would probably
36 result in a lower number of deceased donors.

37

38 Moreover, a policy of mandated choice might be met with resistance because family consent would
39 no longer be an important element of organ donation.¹³ For a variety of reasons, including distrust
40 in the health care system and the threat of legal repercussions, members of the public, health care
41 teams, hospitals, and organ procurement organizations may be reluctant to support a system that
42 limits or discounts families' preferences regarding such a sensitive area as organ procurement
43 following death.¹³

44

45 Findings in the states of Virginia and Texas, both of which have tested the impact of having a
46 mandated choice policy in the last two decades, suggest that such a system could be detrimental to
47 organ procurement. When the state of Virginia adopted a policy of mandated choice, more than
48 24% refused to report a preference.¹⁴ In Texas, a law enacting mandated choice for Texans was

1 repealed after almost 80% of the people chose not to donate organs, provoking a decrease in the
2 number of available organs.¹³

3
4 THE NEED FOR DATA FROM RESEARCH STUDIES

5
6 Even if ethically appropriate models of presumed consent or mandated choice for deceased
7 donation could be implemented, it remains unknown how they would affect the number of organ
8 donations. Properly designed studies, performed at a small scale, could help provide factual
9 evidence that would inform the debate regarding the merits of either policy.

10
11 For presumed consent, for example, studies could measure the change in number of organ
12 transplants, the number of donations, awareness among the public that a presumed consent system
13 was in place, number of documented refusals to donate, how often families claimed to know of
14 refusals, and acceptance by the population of the undermining of individual self-determination.
15 For mandated choice, studies could measure the change in number of organ transplants, the
16 frequency of reaching individuals to offer the opportunity to consent or refuse, the number of
17 documented consents and refusals to donate, understanding of donation by those making choices,
18 the incidence of refusal to make a choice, and acceptance of the mandate by the population being
19 studied.

20
21 The Council believes that unless data from well designed studies suggest a positive effect on
22 donation, neither presumed consent nor mandated choice for deceased donation should be widely
23 implemented. This would help avert the costs of implementing a new system that could fail to
24 increase the number of transplantable organs.

25
26 CONCLUSION

27
28 The present organ procurement system has failed to meet the continuously increasing demand for
29 donor organs, despite intense educational efforts. Part of the problem has been attributed to the
30 fact that individuals do not make known whether they would want to donate their organs.

31
32 One possible way to increase the number of deceased donors involves changing the consent
33 process for organ donation to a system of mandated choice or to a system of presumed consent.
34 While such policies could be implemented in an ethical manner, both models face obstacles that
35 make it necessary to obtain data that suggest a positive effect on donation.

36
37 RECOMMENDATIONS

38
39 The Council on Ethical and Judicial Affairs recommends that the following recommendations be
40 adopted in lieu of Resolution 2 (A-04) and that the remainder of this report be filed:

41
42 The supply of organs for transplantation to treat end-stage organ failure is inadequate to meet
43 the clinical need. Therefore, physicians should support the development of policies that will
44 increase the number of organ donors. Two prominent proposals aimed at increasing organ
45 donation would change the approach to consent for deceased donation: mandated choice and
46 presumed consent.

47
48 Under a presumed consent model, deceased individuals are presumed to be organ donors
49 unless they indicate their refusal to donate. Such donations would be ethically appropriate

1 only if it could be determined that individuals were aware of the presumption and if effective
2 and easily accessible mechanisms for documenting and honoring refusals to donate were
3 established. Moreover, physicians could proceed with organ procurement only after
4 verifying that there was no documented prior refusal by the decedent and that the family was
5 unaware of any objection to donation by the decedent.

6
7 Under a mandated choice model, individuals are required to express their preferences
8 regarding organ donation at the time of performing a state-regulated task. This contrasts with
9 the widespread model of voluntary organ donation under which individuals are afforded an
10 opportunity to indicate their preferences. A mandated choice model would be ethically
11 appropriate only if an individual's choice were made in accordance with the principles of
12 informed consent, which would require a meaningful exchange of information. Physicians
13 could proceed with organ procurement only after verifying that an individual's consent to
14 donation was documented.

15
16 It is not known whether implementation of ethically appropriate models of presumed consent
17 or mandated choice for deceased donation would positively or negatively affect the number
18 of organs transplanted. Therefore, physicians should encourage and support properly
19 designed pilot studies, in relatively small populations, that investigate the effects of these
20 policies. Unless there are data that suggest a positive effect on donation, neither presumed
21 consent nor mandated choice for deceased donation should be widely implemented.

22
23 In all models, education of individuals to facilitate informed consent is requisite.

24
25 (New HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than \$500 to implement.

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service, the chief resident, a designated member of the institutional grievance committee, or, in large institutions, an institutional ombudsperson largely outside of the established hospital staff hierarchy.

4. In accordance with recommendation 3, medical students, resident physicians and other staff should refuse to participate in patient care ordered by their supervisors in those rare cases in which the orders reflect serious errors in clinical or ethical judgment, or physician impairment, that result in a threat of imminent harm to the patient. In these rare cases, the complainant may withdraw from the care ordered by the supervisor, provided that withdrawal does not itself threaten the patient's immediate welfare. In any event, it is essential that the student, resident physician or staff member communicate his or her concerns to the physician issuing the orders and, if necessary, to the appropriate persons for mediating disputes requiring immediate resolution, as defined in recommendation 3 above. Retaliatory or punitive actions against complainants are unethical and are a legitimate cause for filing a grievance with the appropriate institutional committee.
5. Access to employment and evaluation files should be carefully monitored to remove the possibility of inappropriate alteration or tampering. Resident physicians should be permitted access to their employment files and also the right to copy the contents thereof, within the provisions of applicable federal and state laws.

(References pertaining to Report 1 of the Council on Ethical and Judicial Affairs are available from the Office of the General Counsel.)

2. STRATEGIES FOR CADAVERIC ORGAN PROCUREMENT: MANDATED CHOICE AND PRESUMED CONSENT (RESOLUTION 6, A-93)

HOUSE ACTION: RECOMMENDATIONS ADOPTED IN LIEU OF RESOLUTION 6 (A-93) AND REMAINDER OF REPORT FILED

INTRODUCTION — THE SCARCITY OF ORGANS FOR TRANSPLANTATION

Resolution 6, introduced at the 1993 Annual Meeting by the Medical Schools Section and referred to the Board of Trustees, called upon the AMA to review various options to enhance the availability of transplantable organs. The Council responds with this report and with a companion report on the use of financial incentives for organ donation.

The shortage of organs for transplantation is becoming more critical every year. Because of improvements in transplantation procedures, beginning with the advent of immunosuppressive therapies in the early 1980s, increasingly large numbers of patients can now benefit from organ transplantation. As a result of transplantation's success, waiting lists for donor organs are increasingly crowded. Between December 1987 and June 1991, for example, the total number of patients on organ transplant waiting lists increased 75.3 percent, from 13,153 to 23,056 patients.

Tragically, the supply of donated organs has not kept up with this demand. Between 1987 and 1990, the number of organ donors per year stayed nearly constant, increasing from 4,000 to 4,357. Even though each cadaveric organ donor can often supply multiple organs for transplantation, many patients still die before a suitable organ becomes available. The United Network for Organ Sharing in September 1991 estimated that at least 8.7 percent of patients needing a liver transplant die before an organ becomes available; other estimates have put this figure closer to 30 percent. Over one three month period in 1991, nearly 500 transplant candidates died waiting for organs.

Clearly, the shortage of organs for transplantation results in a tragic number of potentially preventable deaths. Since organs are retrieved from only about 15 to 20 percent of the 15,000 to 20,000 eligible cadaveric donors available each year, increased efforts to encourage organ donation could save many more lives.

In the current system of organ donation, organs may be procured from cadaveric donors only if the decedent has previously expressed a desire to donate, or, in the absence of clear evidence of the decedent's wishes, consent is obtained from the decedent's family. The chronic shortage of organs for transplantation, however, has prompted many proposals for reforming the current system of organ donation in the hopes of increasing the supply of organs. In this report, the Council explores two proposals for increasing the organ supply from cadaveric donors: mandated choice and presumed consent.

MANDATED CHOICE

Under mandated choice, individuals would be required to state their preferences regarding organ donation when they renew their driver's licenses, file income tax forms, or perform some other task mandated by the state. By requiring that a decision regarding donation be made, a major obstacle to organ donation — the reluctance of individuals to contemplate their own deaths and the disposition of their bodies after death — would be effectively overcome, and individual autonomy would be protected and even enhanced.

Public opinion polls show that one major reason why people currently do not sign donor cards or otherwise indicate a desire to be organ donors, even when they support the concept of organ donation, is a widespread reluctance to consider one's own death and the prospect of bodily mutilation that organ harvesting would entail. Under mandated choice, individuals who do feel this reluctance would have to confront it, thereby removing it as a barrier to donation.

Requiring individuals to make a choice about organ donation when they would rather not face the issue may be considered by some to be coercive or an invasion of privacy. However, this objection holds little weight when the costs of mandated choice is compared to the social benefits of such a policy. Mandated choice could be carried out in conjunction with another state-mandated task, such as renewing a driver's license, and would not require additional expenditures of time and energy by the individual. Given the pressing need for organs by increasing numbers of patients, requiring merely that a choice be made seems a small price to pay for the possibility of saving more lives. In addition, mandated choice is in no way coercive with regards to the particular choices individuals make; individuals who do not want to serve as organ donors, for whatever reason, are free to say no.

By requiring all competent adults to make the donation decision for themselves, in advance of illness, mandated choice promotes individual autonomy in organ donation decisions. As stated in the Uniform Anatomical Gift Act, adopted with minor variations by all fifty states and the District of Columbia, "an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death." The UAGA's emphasis on individual autonomy and individual decisionmaking would be protected and enhanced by a system of mandated choice, in which the donation decision would have to be confronted before death and would have to be made by the individual donor, not by a surrogate.

Also, by requiring that individuals make their preferences clear, mandated choice would reduce the stress placed by the current system on the families and physicians of dead or dying patients whose organs could be suitable for harvesting. Under the current system, "required request" laws mandate that physicians or other hospital personnel approach the decedent's family to ask permission to remove the decedent's organs when the decedent's own preferences are unknown. Families grieving over the sudden, unexpected death of a loved one often resent the timing of such requests, which usually must be answered within a few hours in order for the organs to remain viable for transplantation. Physicians, too, often find it extremely difficult to make these requests, both because of the probable reaction from the family and their own sense of loss after the death of their patient. As a result, too often requests are not made, or else families resenting the intrusion refuse to consent.

Under mandated choice, families and physicians would know for certain the individual's preferences, eliminating the need for agonizing decisions by the family that may not accurately reflect the individual's true preferences. In addition, clear knowledge of the decedent's preferences may make it easier for families who might be opposed to accept the decision to donate. One recent survey indicated that 93 percent of Americans would honor the expressed wishes of their family member regarding organ donation if those wishes were known. While mandated choice may not completely suppress the efforts of some families to override decedents' preferences regarding donation, it could discourage such "family vetos" by making the decedent's wishes indisputably clear.

There is also empirical evidence that mandated choice would be acceptable to the public and effective in increasing the organ supply. In Colorado, where citizens are required to indicate on their driver's licenses whether they would be willing to serve as organ donors, it has been reported that 60 percent of all drivers are designated organ donors, much higher than the 2-8 percent rate found in four other states studied that do not employ mandated choice. In addition, in an initial survey of public opinion on mandated choice, approximately 90 percent of respondents indicated they would support such a program.

Given the success of mandated choice in Colorado and its reliance on the voluntary choices of autonomous individuals, mandated choice is a promising strategy for increasing the supply of organs for transplantation and should continue to be pursued. Mandated choice respects and promotes individual decisionmaking and would ease the stress placed on physicians and families when decedents have not expressed their own wishes regarding organ donation.

PRESUMED CONSENT

Under presumed consent, it would be assumed that people consent to be cadaveric organ donors, unless they or their families register an objection. Thus, in contrast to the current system, in which people are given the opportunity to "opt in" to the organ donation system by signing a donor card or otherwise expressing their desire to be organ donors, under presumed consent individuals would be in the system unless they decide to "opt out" by registering their refusal to donate.

Presumed consent raises important ethical concerns that would preclude its use when there is no effective mechanism for documenting and honoring decisions to opt out of the system. When there is an effective opting-out system, however, presumed consent may be ethically acceptable. Below, the benefits and detriments of a policy of presumed consent are considered in full.

Constitutional Issues

Presumed consent exists in several states in laws permitting coroners or medical examiners to remove corneas, pituitary glands, and other tissues specified by statute from cadavers when there is no knowledge of any objection to the removal from the decedent while living or the decedent's family. In some states, these laws have been challenged on constitutional grounds. Plaintiffs have claimed that removing organs in the absence of any objection, rather than with the donor or the family's express consent, violates the fifth amendment's prohibition on the taking of private property without due process and just compensation. Recent court decisions suggest that the constitutionality of presumed consent may be in doubt when there is not an effective system for documenting and honoring objections to donation. However, when there is an effective opting-out system, most commentators agree that presumed consent is constitutional.

Effectiveness in Increasing the Organ Supply

Presumed consent may do a better job than a system of express consent in making more organs available for transplantation. For instance, a comparison of six European countries in 1990 showed significantly higher rates of organ transplantation in Belgium, France and Austria, which operate under presumed consent, than in the United Kingdom, Germany and the Netherlands, which operate under an "opting-in" system. Belgium experienced

a reported 140 percent increase in the total number of organs available for transplantation following its move from an express consent system to a system of presumed consent, although a substantial portion of this increase may be attributable to the increased number of hospitals participating in organ procurement rather than to the initiation of presumed consent.

Presumed consent may be effective by altering the consent process in undesirable ways. For instance, one way in which presumed consent facilitates organ procurement is by reducing the role of family input in the decision-making process. In fact, in some European countries operating under presumed consent, family input is largely eliminated. Physicians may remove organs as long as there is no known objection, and physicians have no obligation to inform the family of the practice or to give them an opportunity to protest. Some commentators argue that it is more humane not to discuss the issue of organ donation with the family, for such discussions only add an extra burden to their grief. However, excluding the family entirely is ethically troublesome because it overlooks cases in which the family has knowledge of the decedent's preferences that the physicians may lack.

Respect for Individual Preferences

Systems of presumed consent that fail to verify the absence of objections — for instance, by excluding families from the decisionmaking process — are ethically problematic because they may fail to respect individual preferences regarding organ donation. The individual's interest in controlling his or her own body, even after death, is a widely accepted value in organ transplantation and other medical contexts.

Recognizing this value, some proponents defend presumed consent on the grounds that it enhances the autonomy of the individual serving as the source of the organs. Opinion polls document high levels of public support for organ donation and transplantation. In a 1990 Gallup poll 85 percent of those surveyed said they would donate a loved one's organs, and 60 percent said they would donate their own organs. Thus, when a potential donor has not clearly expressed his or her preferences (as often happens), a decision to harvest the organs is more likely to be in accordance with what the individual would have wanted than a decision not to harvest the organs.

However, the claim that presumed consent enhances individual autonomy is dubious. In many cases, it is incorrect to assume that an individual who does not clearly express a preference would in fact be willing to serve as an organ donor. If 60 percent of the population would be willing to donate their own organs, this means that the presumption of consent would be incorrect up to 40 percent of the time. (In fact, the estimate that 60 percent would actually be willing to donate their own organs may be inflated; the number of people who actually register their willingness by signing a donor card has generally fallen short of this mark.

Proponents of presumed consent could argue that this 40 percent could choose to opt out of the system by registering their refusal to serve as organ donors. However, opting out of the system is a viable option only for those patients who understand how the system works and know how to express their objections to donation. In addition, given the evidence that a major factor deterring donation under the current system is a general reluctance to think about death and post-mortem surgery, some people could be just as reluctant to register a refusal as they are now to register their consent (by completing an advance directive or donor card). Thus, organs could be retrieved not because the decedent's failure to opt out actually indicates a willingness to opt in, but rather because of the decedent's failure to overcome inertia and confront the decision squarely. Furthermore, in light of the pressing need for transplantable organs, there may be an incentive under presumed consent to avoid discussions with patients and their families concerning organ donation, for fear of discovering objections that would preclude organ retrieval. As mentioned, this has already happened in some European countries. When individuals and families are not told that they can object or how to object to organ donation, presumed consent becomes in effect a strategy for avoiding consent entirely. Though proper safeguards could help ensure that individuals would be told of their right to opt out, safeguards will be difficult to maintain when there is the constant incentive to avoid the issue. The resulting reduction in efforts to educate and inform patients about organ donation and the success of organ transplantation could increase public mistrust and negatively impact the success of organ procurement efforts in the long run.

Thus, far from enhancing individual autonomy, presumed consent actually would be more likely than systems of express consent to harvest organs against the true wishes of individuals and their families. More organs may be procured under presumed consent, but only because such a system takes advantage of the public's general reluctance to dissent and the ignorance or temporary confusion of those who do not wish to donate but do not register their objection. If one goal of the organ procurement system is to avoid organ harvesting against the individual's true preferences, a better approach would be to encourage or even require individuals to make their preferences clearly known in advance, as in mandated choice, rather than presume consent or force families to make the decision for them.

Promotion of Communitarian Ethic

Some proponents of presumed consent reject the traditional emphasis on individual autonomy in donation decisions. Placing too great an importance on individual rights and autonomy ignores fundamental moral obligations incurred by individuals as members of society. An opting-out system that assumes people will be willing to donate reflects a more communitarian outlook that respects the needs of the larger community as well as those of the individual.

The communitarian view holds that individuals have a moral duty to help others when the cost to the individual of helping is very low, especially in matters of life and death. Thus, since cadaveric organ donation can save the lives of others and causes no significant harm to the decedent or the family, individuals who do not object on religious grounds have a moral duty to donate their organs. An opting out system recognizes this moral duty by making consent to donation the norm; those opposed to donation would bear the burden of making their objections known. Making donation the norm may also help foster greater communal attachments and feelings of solidarity.

The communitarian argument must be considered seriously, for it directly challenges a basic presupposition of current organ procurement efforts — that consent to donation should be considered an act of charity, a gift freely given — and counters that donation should instead be understood as the expected response to the individual's moral obligation to benefit others. Some disagree that such a duty even exists: "Although we have a duty not to harm another, it is not so clear that anyone has a duty to help others when the help entails the postmortem surrender of a part of the body." Others support the thesis that organ donation is a duty but disagree that this duty should be codified in the law. Instead, individuals should be called upon to fulfill this duty voluntarily, on their own personal volition, rather than through a system of "semi-obligatory public beneficence." Only through active, voluntary compliance with duty, it is argued, can true communal attachments be fostered.

Clearly, conflicting values may be brought to bear on this issue. Generally, the legal system has viewed the duty to help others as a moral duty properly left to the individual's own conscience. However, there are exceptions to this general legal rule; some states have good samaritan laws requiring individuals to attempt an easy rescue of another when in a position to do so, and spending tax dollars on social programs that support the indigent arguably reflects society's recognition of the duty to help others. The difficulty in applying this duty to organ donation, however, is that it requires an invasion of bodily privacy that does not occur in other contexts. Most individuals, as one commentator writes, "draw a thick but not impenetrable line at the body's perimeter," so that no matter what else may befall them, their bodies, at least, are theirs to command. Though some would argue that requiring express consent for invasions of the body should apply only to the living, who unlike the dead might suffer real harm if policies requiring express consent were rescinded, the Council feels that control over the disposition of the dead should remain governed by individual and familial values rather than by a communitarian ethic.

CONCLUSIONS

Presumed consent for organ donation raises a number of concerns, including the danger that individual preferences regarding donation will be ignored. To be ethically acceptable, presumed consent would require intensive, sustained educational efforts to inform individuals and families of their right to opt out of the system by registering

an objection to donation. The mere absence of known objections does not mean that consent may be presumed; rather, when a decedent has not indicated his or her preference regarding donation, families must be approached to see if they have knowledge of the decedent's true wishes.

Some proponents argue that presumed consent could be effective even if the family is routinely contacted. In this version, families would not be asked to consent to donation, but only to verify that they do not object. This would "allow physicians to broach the issue (of donation) as a matter of hospital and societal routine, while merely requiring the inaction of informed next-of-kin." Some commentators doubt that this approach could be effective; the same families that object to donation under the current system of required request would still object under presumed consent if given the opportunity. Thus, though this version of presumed consent does incorporate an adequate opting-out mechanism and therefore is ethically acceptable, it is unlikely to be much more effective in procuring organs than the present system.

RECOMMENDATIONS

In lieu of Resolution 6 (A-93), the Council on Ethical and Judicial Affairs recommends that the following guidelines be adopted:

1. A system of mandated choice for organ donation, in which individuals are required to express their preferences regarding organ donation, is an ethically appropriate strategy for encouraging people to become organ donors and should be pursued. The AMA should work with state medical societies to draft model legislation for implementing a policy of mandated choice and should encourage its adoption by state legislatures. To be effective, information on the importance of organ donation and the success of organ transplantation must be provided when the donation decision is made.
2. A system of presumed consent for organ donation, in which individuals are assumed to consent to be organ donors after death unless they indicate their refusal to consent, raises serious ethical concerns. For presumed consent to be ethically acceptable, effective mechanisms for documenting and honoring refusals to donate must be in place. In addition, when there is no documented refusal by the individual, families of decedents would have to be routinely contacted to verify that they do not know of any objections to donation by the decedent while living.

(References pertaining to Report 2 of the Council on Ethical and Judicial Affairs are available from the Office of the General Counsel.)

3. THE USE OF MINORS AS ORGAN AND TISSUE SOURCES

HOUSE ACTION: RECOMMENDATIONS ADOPTED AND REMAINDER OF REPORT FILED

INTRODUCTION

The transplantation of a human organ or tissue raises difficult ethical questions when the potential source is a minor child. (Because minors generally cannot give valid consent to donation, this report will use the term "source" instead of "donor" when referring to minors.) Unlike therapeutic medical treatment, organ or tissue retrieval is performed for the benefit of another person and places the source at some medical risk. Though society respects adults' decisions to assume the risks of organ donation, minors generally do not enjoy the same legal status with regard to consent to non-beneficial medical procedures and may lack the capacity to decide for themselves. Other persons, such as parents or guardians, are often required to make decisions on behalf of minors, and are generally expected to make choices that result in benefit rather than harm. These considerations raise the following questions