

6.1.3 Studying Financial Incentives for Cadaveric Organ Donation

Physicians' ethical obligations to contribute to the health of the public and to support access to medical care extend to participating in efforts to increase the supply of organs for transplantation. However, offering financial incentives for donation raises ethical concerns about potential coercion, the voluntariness of decisions to donate, and possible adverse consequences, including reducing the rate of altruistic organ donation and unduly encouraging perception of the human body as a source of profit.

These concerns merit further study to determine whether, overall, the benefits of financial incentives for organ donation outweigh their potential harms. It would be appropriate to carry out pilot studies among limited populations to investigate the effects of such financial incentives for the purpose of examining and possibly revising current policies in the light of scientific evidence.

Physicians who develop or participate in pilot studies of financial incentives to increase donation of cadaveric organs should ensure that the study:

- (a) Is strictly limited to circumstances of voluntary cadaveric donation with an explicit prohibition of the selling of organs.
- (b) Is scientifically well designed and clearly defines measurable outcomes and time frames in a written protocol.
- (c) Has been developed in consultation with the population among whom it is to be carried out.
- (d) Has been reviewed and approved by an appropriate oversight body, such as an institutional review board, and is carried out in keeping with guidelines for ethical research.
- (e) Offers incentives of only modest value and at the lowest level that can reasonably be expected to increase organ donation.

AMA Principles of Medical Ethics: I,III,V,VII,VIII,IX

Background report(s):

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

CEJA Report 1-A-02 Cadaveric organ donation: encouraging the study of motivation

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 1-A-02

Subject: Cadaveric Organ Donation: Encouraging the Study of Motivation

Presented by: Frank A. Riddick, Jr., MD, Chair

Referred to: Reference Committee on Constitution and Bylaws
(C. Richard Schott, MD, Chair)

1 INTRODUCTION

2
3 About 6,000 patients per year, or 16 per day, with end-stage organ failure die because of the lack of
4 available organs. Each year only 35-50% of potential donors consent to donation.¹ Over the last 20
5 years, vigorous educational campaigns, both voluntary and legislative, designed to increase organ
6 donation have failed to increase donation rates significantly. The need for organs has grown nearly 5
7 times faster than the number of cadaveric donors: the annually compounded rate (1990-2000) of increase
8 in number of patients on waiting lists has averaged 14.1% a year, while the rate of increase of donors has
9 averaged 2.9% a year.² The AMA has been concerned about this problem for many years, and has
10 developed several policies addressing it in the past decade.³ AMA policy has supported certain forms of
11 financial incentives for cadaveric organ donation since 1993 (Policy E-2.15, AMA Policy Database), but
12 they have never been implemented because federal law prohibits them. AMA policy specifically
13 prohibits payment to living donors.⁴

14
15 Most initiatives to increase organ donation have focused on what motivates or hinders the decision to
16 donate. Programs to improve organ donation rates have been aimed at public and professional groups.
17 These have included widespread educational campaigns aimed at motivating individuals to become
18 donors. They also have included mandated choice legislation, the establishment of the Organ
19 Procurement and Transplantation Network (OPTN), donor card programs, donor registries, and the
20 creation of specialized organ donation teams within hospitals that discuss organ donation with families
21 and patients. Despite these efforts, cadaveric donation rates have remained nearly stable over the past
22 decade.

23
24 This report encourages the medical and scientific communities to reexamine motivation for cadaveric
25 organ donation. Building on CEJA's work in 1993, which led to Opinion 2.15, "Financial Incentives for
26 Organ Donation," this report identifies reasons why ethical objections to financial incentives, for
27 cadaveric organ donation only, should be reexamined. In particular, this report considers the need to
28 study the impact of financial incentives through limited research trials. Such studies would help measure
29 the effect of incentives not only on donation rates but also on public perception of the transplant
30 enterprise and of the meaning of organ donation.

31
32 For the purposes of this report, donation and procurement of organs are completely independent from the
33 allocation of organs. The report neither suggests nor supports any change in the current system of organ
34 distribution, as developed and administered by the United Network for Organ Sharing (UNOS). Even if

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on 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.

A version of this Report was published as "Cadaveric organ donation: Encouraging the study of motivation" (*Transplantation*. 2003; 76(4): 748-751).

1 financial incentives were found to have a positive impact on cadaveric organ donation rates, allocation
 2 algorithms developed by the OPTN would continue to govern organ distribution, and transplant recipients
 3 would continue to be selected according to ethically appropriate criteria related to medical need rather
 4 than ability to pay.

5
 6 Physicians have an obligation to hold their patients’ interests paramount and to support access for all
 7 patients to medical care (Principles VIII and IX). To discharge these obligations, physicians should
 8 participate in efforts to increase organ donation, including education of their patients and the general
 9 public regarding the importance of organ donation, and promotion of voluntary donation of organs.
 10 Beyond educational programs, however, physicians should support innovative approaches to encourage
 11 organ donation. Such efforts include encouragement and, if appropriate, participation in the conduct of
 12 ethically designed research studies of donor motivation. A potential impetus for cadaveric organ donation
 13 that has not been adequately explored (because of federal prohibition) is financial incentives. Such
 14 incentives are not intrinsically unethical; AMA policy has supported them since 1993. Whether a
 15 particular incentive is ethical or not depends upon the balance of benefits and harms that result, and these
 16 are currently unknown because they have never been investigated.

17 18 DONOR MOTIVATION

19
 20 The National Organ Transplant Act of 1984 (NOTA) forbade the provision of any “valuable
 21 consideration” to organ donors, ruling out any form of reward or compensation of expenses engendered
 22 by donation.⁵ It also created the OPTN to be managed by a private nonprofit organization. The contract
 23 was awarded to UNOS.

24
 25 While one of the major purposes of UNOS is to encourage organ donation, it is the position of UNOS that
 26 the only ethically sound motivation for donation is altruism (i.e. the absence of any personal benefit
 27 beyond the satisfaction of giving).⁶ Thus, most of the educational and motivational campaigns to increase
 28 donation have appealed to the altruistic aspect of saving the lives of others. Some feel that appealing only
 29 to potential donors’ altruistic motivations is limiting and may foreclose a broad range of programs that
 30 also might motivate organ donation. Others feel that diluting the altruistic intent of donating organs
 31 might undermine important social values and elicit negative responses that could decrease the number of
 32 organ donors. Both sides are likely to agree, however, that determining how best to motivate a person to
 33 become an organ donor is essential to increasing the number of potential donors.

34
 35 Considering that the most common reason for missed donation opportunities is denial of consent by the
 36 donor’s family,⁷ any effort to increase the rate of organ donation would likely need to be directed beyond
 37 individuals in order to reach donor families as well. Many states have enacted or are currently
 38 considering legislation that would prohibit a family from overruling a patient’s documented wish to be an
 39 organ donor.⁸ Yet, it is still unclear whether prohibiting families from overriding documented wishes
 40 would result in a net increase of organs. This strategy, like others aimed to increase the number of organs
 41 available for transplant, must continue to receive careful consideration.

42 43 *Potential Strategies*

44
 45 In a survey of the general public, 85% of respondents supported organ donation and 69% of those
 46 surveyed indicated that they were likely to want their own organs to be donated.⁷ In practice, requests for
 47 donation are granted only about half the time. This decline in people’s support for donation between the
 48 time they answer a questionnaire and the time they are asked to authorize the donation of a deceased
 49 person’s organs may be explained in part by the fact that transplantable cadaveric organs are usually
 50 obtained from people who died suddenly in an unexpected and untimely manner. Families are asked about
 51 donation at a time when they are deeply distressed. Also, many people have religious or personal beliefs

1 that bodies should be buried intact. Others may not trust the health care system as a whole, or the
 2 providers who were involved in the care of their now deceased relative. Still others have deep
 3 misunderstandings about the meaning of brain death, or about the value of transplantation, and may not be
 4 open to learning more about these matters when they are facing the loss of a loved one.

5
 6 Financial incentives, carefully determined at the lowest level that can reasonably be expected to
 7 encourage cadaveric organ donation, might provide additional motivations; several models have been
 8 proposed. By entering into a future contract, a competent adult would agree to donate organs after death.
 9 In return, the appropriate agency would agree to provide some financial remuneration to the donor's
 10 family or estate after the organs had been retrieved and judged suitable for transplantation.⁹ A bill
 11 currently before Congress, as another example, would allow for the implementation of a future contract
 12 that includes a tax credit of up to \$10,000 on the estate of the deceased donor. CEJA's Report, "Financial
 13 Incentives for Organ Procurement: Ethical Aspects of Future Contracts for Cadaveric Donors," supports
 14 the implementation of a pilot program to study the influence of future contract incentives on organ
 15 donation rates. Another proposal that would produce financial benefit directly to the donor's family has
 16 been developed in Pennsylvania, where a law was passed that allows payment of \$300 toward funeral
 17 expenses incurred by the family of the donor. However, this program has still not been implemented
 18 because of NOTA's prohibition against any valuable consideration for organ donation.

19
 20 Direct monetary payments to families who agree to donation has also been recommended.^{10,11, 12} One
 21 study has shown that payment of \$500 to \$1000 for donation would increase donation rates sufficiently to
 22 nearly eliminate the kidney waiting list.¹⁰

23 24 *Concerns*

25
 26 The degree to which any financial incentive will diminish the number of patients who die on the waiting
 27 list each year is unknown. Therefore, the potential benefits to be gained from each proposal discussed
 28 above remains speculative and must be weighed against possible harms before any such program is
 29 widely implemented. This highlights the importance of conducting research studies of sound scientific
 30 design. For example, if research shows that little discernable harm to potential donors or their families
 31 results from offering modest financial incentives, thereby saving more lives through increased organ
 32 donation rate, everyone benefits. But if certain harms are found, physicians and policymakers will need
 33 to search for other means of increasing donation rate.

34
 35 Only through research can the social implications of incentives be understood, including the possibility
 36 that they might dilute a desirable spirit of altruism, might imply that the human body and its parts can be
 37 treated as commodities, or that voluntariness of organ donation would be critically undermined.^{12, 13}

38 39 Reducing Altruism

40
 41 Under the existing organ procurement system, the only acceptable motivation for organ donation is
 42 altruism. Many who are opposed to financial incentives fear that removing organ donation from an
 43 altruistic framework would alienate people who until now have supported organ donation. They are
 44 concerned that, as a result of introducing these incentives, the number of potential donors would decrease.
 45 It should be noted, however, that a fall in donor numbers has not been observed in the context of blood
 46 donation, where payment for blood has been introduced in addition to voluntary programs.

47
 48 Moreover, financial incentives per se may not eliminate altruism as a motivation for organ donation. The
 49 motive to donate may be in part self-interested if there is an incentive, but still accompanied by altruistic
 50 motives. Because altruism is a personal characteristic, it is possible that a certain level of financial

1 incentive may be sufficient to change a non-donor to a donor, while having no effect at all on that
2 individual's nor the overall level of society's altruism.

3
4 Financial benefits to families could be viewed as a token of societal gratitude, similar to tax incentives for
5 donations to charitable organizations.¹³ The degree to which altruism might be changed by financial
6 incentives remains unexplored even though appropriately designed research studies could provide
7 measurable evidence to help answer this question.

8 9 The human body as a commodity

10
11 Another argument in opposition to incentives holds that such programs would fuel an already disturbing
12 trend towards viewing the human body as a source of profit. Although it is acknowledged that one's body
13 is significantly different from other forms of property, some limited ownership rights to the body are
14 recognized.¹³ For example, blood and some other tissues can be sold. There seems to be no compelling
15 ethical argument why viable solid organs should be treated differently from those other tissues.
16 Moreover, the current means of organ donation themselves imply some notion of property right since
17 "one cannot give away what one does not own any more than one can sell it."¹³ Moreover, it is important
18 to recognize that organs are attributed some value and paid for, albeit indirectly, by the overall cost of the
19 procedure. Yet, donors are the only component in the current system who do not stand to benefit
20 materially from the transplant.

21
22 Finally, given the pluralistic expression of religious and moral beliefs tolerated and even encouraged in
23 this country, the extent to which such commodification could be viewed as disrupting our social fabric is
24 unclear.¹⁴ Research studies, relying on available sociological methodologies will help determine the
25 impact of incentives on our social fabric.

26 27 Voluntariness of consent

28
29 Fundamental to the concept of consent is the element of voluntariness. To coerce a person into making a
30 medical decision is to violate the person's right to make an autonomous decision concerning the use of his
31 or her body. Thus, protecting the voluntariness of the decision to become a donor must remain an
32 important consideration for any program offering financial incentives.

33
34 In particular, some hold that socioeconomically disadvantaged individuals or their families would more
35 easily be influenced to become donors due to their financial situation, seriously undermining society's
36 egalitarian ideals and placing much of the burden of organ donation on those less well off. However, we
37 find little difficulty in allowing poorer members of society to make many choices due to their financial
38 circumstances, such as working at jobs avoided by most because they are undesirable, uncomfortable, or
39 dangerous. Some have argued that the idea of coercion is best understood as forcing others to do things
40 they would not otherwise choose to do.

41
42 Even if such concerns were valid, financial incentives such as tax credits or payment to a charitable
43 organization selected by the donor could reduce the possibility of undue influence. For example, in the
44 case of tax credits, the donor would have to possess a significant estate to take advantage of the tax credit.
45 Overall, programs could be conceived that would combine direct payments and estate tax credits so that
46 donation would be equally attractive over the entire socioeconomic spectrum.

47
48 In the case of future contracts, some have argued that they would appeal mostly to lower socioeconomic
49 groups, who would therefore bear most of the burden of organ donation. Others have countered that it is
50 paternalistic to deny the poor a choice that could improve their condition.

The Need for Data from Research Studies

In the previous section, ethical concerns regarding the potential harms that could come from the use of financial incentives for organ donation were surveyed. However, it is important to note that there is a dearth of scientific data supporting those concerns. Nearly all of the arguments against financial incentives are based on assumptions that can be proved or disproved by scientific studies. Factual evidence that would determine the presence or absence of harm to individuals or groups of individuals could in fact resolve many of the policy debates between those who object to financial incentives for cadaveric organ donation and those who favor such incentives.

A thorough discussion of this matter also must include an examination of the costs of foregoing such studies. Currently, about 16 patients die each day waiting for an available organ.¹⁵ If policymakers, ethicists, or legislators prohibit the implementation of programs that could be shown to increase the number of available organs and reduce the number of deaths, then they must bear some moral responsibility for the patients who die from lack of an organ transplant. Therefore, a better informed debate is necessary, one that can occur only after the effectiveness of various incentive models has been measured.

CONCLUSION

Thousands of patients with end-stage organ failure die each year because most potential donors do not consent to donation. For two decades, vigorous educational campaigns, both voluntary and legislative, designed to increase organ donation have failed to increase donation rates significantly. More innovative methods to increase the number of cadaveric donations are required to help supplement current initiatives and address the shortage that can be tested in limited research studies.

Research studies should be undertaken to measure the impact of incentives on the rate of donation and on some of the values that, until now, have been assumed to be central to organ donation, namely altruism, the non-commercial nature of the body and its parts, and the voluntariness of donation. Because of the uncertainty of benefits and harms that might arise and because of likely resistance by some to the idea of financial incentives, initial studies should be limited in scope. Such studies should be designed carefully so as to meet all ethical standards and scientific design requirements that are generally applied to research. Moreover, given the pluralism of American society, any research studies should be consistent with the needs, values, and mores of the particular population under study; therefore, these initiatives should solicit guidance and advice from the intended study population at the outset. All proposed investigational protocols should be reviewed and approved by appropriate oversight bodies, such as Institutional Review Boards. The research studies should be limited to small populations, have clearly measurable outcome variables to assess their effectiveness, and should be completed within defined time frames.

The AMA has had policy supporting certain forms of financial incentives for cadaveric organ donation since 1993 (Policy E-2.15, AMA Policy Database), but they have never been implemented because federal law prohibits them. Congressional action would be required to waive the law for all such research studies. However, we have provided reasons to pursue research studies, in order to obtain much needed data on the effectiveness of incentives in increasing the rate of donation without causing harm to patients or groups of patients, and without damaging the social fabric or undermining the ethical foundations of transplantation.

1 RECOMMENDATIONS

2
3 The Council recommends that the following be adopted and the remainder of the report be filed:

4
5 Physicians have an obligation to hold their patients’ interests paramount and to support access to
6 medical care (Principles VIII and IX). To discharge these obligations, physicians should
7 participate in efforts to increase organ donation including promotion of voluntary donation.
8 Beyond educational programs, however, physicians should support innovative approaches to
9 encourage organ donation. Such efforts may include encouragement and, if appropriate,
10 participation in the conduct of ethically designed research studies of financial incentives.

11
12 Because the potential benefits and harms of financial incentives for cadaveric organ donation are
13 unknown, physicians have an obligation to study financial incentives. Whether or not they are
14 ethical depends upon the balance of benefits and harms that result from them. Physicians should
15 encourage and support pilot studies, limited to relatively small populations, that investigate the
16 effects of financial incentives for cadaveric organ donation for the purpose of examining and
17 possibly revising current policies in the light of scientific evidence.

18
19 Pilot studies of the effects of financial incentives for cadaveric organ donation should be
20 implemented only after certain considerations have been met, including:

- 21
22 (1) consultation and advice is sought from the population within which the pilot study is to take
23 place;
- 24
25 (2) objectives and strategies as well as sound scientific design, measurable outcomes and set time
26 frames are clearly defined in written protocols that are publicly available and approved by
27 appropriate oversight bodies, such as Institutional Review Boards;
- 28
29 (3) incentives should be of moderate value and at the lowest level that can be reasonably
30 expected to increase organ donation;
- 31
32 (4) payment for an organ from a living donor should not be part of any study;
- 33
34 (5) financial incentives should apply to *cadaveric donation* only, and must not lead to the
35 purchase of donated organs; the distribution of organs for transplantation should continue to
36 be governed by UNOS, based on ethically appropriate criteria related to medical need.

Complete references for this report are available from the Council on Ethical and Judicial Affairs.

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