

Anencephalic Infants as Sources of Transplantable Organs

**by the Ethics and Social Impact Committee,
Transplant Policy Center, Ann Arbor, MI.**

In 1986 the state of Michigan established the Transplant Policy Center to conduct research and examine issues relevant to the formulation of sound public policy on transplantation. One of the Center's six advisory committees, the Ethics and Social Impact Committee, has taken up the question of anencephalic infants as sources of transplantable organs. Its members include two transplant surgeons, two transplant coordinators, a transplant social worker, a nephrologist, an epidemiologist, a neonatologist, a psychiatrist, a nurse educator, a health policy planner, a transplant recipient, two philosophers, and two members of the clergy.

In September 1987, neonatologist John Hartline provided a medical overview of anencephaly, and the committee reviewed the available literature. Subsequent deliberations focused on a pair of position papers: one by Shaké Ketefian, which defended the use of anencephalics as sources of organs; the other by Eugene Grochowski, which opposed it. Later, to ensure that everyone's position was adequately understood and appreciated, each member wrote a short personal position paper that was distributed to the other members.

These papers revealed an emerging consensus on a particular proposal, which I tried to articulate in draft form. This paper provided the basis for a four-hour meeting at which many revisions were proposed. Carl Cohen then prepared a considerably restructured second draft, which was

further refined and eventually ratified in April 1988.

The full report analyzes three major positions: (1) that the removal of transplantable organs from anencephalic infants is impermissible because they are living human beings, and attempting to preserve their organs until they are brain dead treats them as mere means; (2) that the removal of transplantable organs from anencephalic infants is permissible because under a revised conception of death—one that would identify death with total and permanent loss of consciousness—all such infants are dead; and (3) that infants born with the top half of their brains missing are so very different from other living infants—and their future so radically limited—that it is permissible, with the fully informed and freely given consent of the parents, to remove their organs for transplantation. The Committee endorses the third position.

The first, it finds, "is a view so absorbed in principles believed to be right (or wrong) *in the abstract* as to fail to attend to the real and powerful concerns of the living human beings involved." Solace for the parents of the anencephalic infants, the potential benefits for recipients, and the joys successful transplants would bring to recipient's families should also enter moral deliberation.

Although some committee members were philosophically attracted to the second position, all agreed that changing the conception

of brain death would have considerable impact on an array of patients far beyond brain-absent newborns. Thus the committee concludes that, at least at present, "it is not feasible to defend the taking of organs from anencephalic infants on the basis of a changed theory of brain death."

The following excerpt includes the Committee's complete articulation and defense of the third position. The recommendation is now being distributed to interested members of the Michigan legislature.*

Martin Benjamin, Chair
Ethics and Social Impact Committee

Policy Recommendation: Anencephalic infants are suitable organ donors without delay, whatever else may be true about their status.

The philosophical position...we adopt does not reconcile the two above, nor does it seek to resolve the underlying dilemma presented by alternative conceptions of brain death....Hence we cannot say with confidence whether anencephalic infants should be thought of as alive or dead.

We are confident, nevertheless, that as a moral matter, it is right to transplant the organs of such infants to save lives that can be saved only in that way, and we believe that it is wrong to refrain from doing so, if the fully informed consent of the parents has been given. We defend not an *intermediate* position in the conflict recounted above, but a position that *bypasses* that conflict.

The third position holds that anencephaly is a condition so special, so very different from all others, and one whose diagnosis and prognosis can be established with such manifest certainty, that infants in this most unfortunate condition should be viewed as in a class that is entirely *sui generis*, and one for which special rules and laws should apply.

In explaining the philosophical ground of this position, certain features of the real circumstances of

*Readers wishing to review the document in its entirety may write to the Transplant Policy Center, 115 Washtenaw Place, P.O. Box 0716, Ann Arbor, MI 48109-0716.

the brain-absent infant must be emphasized. First, because the condition in question is the physical absence of the entire top of the brain, the presence of that condition can be determined without any dispute. Unlike some other congenital neurological deficits, this is not a condition in which the status of the patient, or the prognosis for the patient, remain in any doubt whatsoever. Second, the brain-absent infant has some vital organs that are normal—heart, liver, kidney—that may save the lives of some other infants who, without such transplantation, will surely soon die. Third, although the anencephalic infant is certainly doomed, if we wait for its expiration under presently accepted guidelines, the potentially life-saving organs will deteriorate and cease to be transplantable.

These being the real circumstances in many cases, we conclude that it is entirely right to transplant those organs without delay, provided that the parents of both the anencephalic and the recipient have been fully informed of the risks and benefits of the procedure and have freely consented to it. There is no human life (as normally conceived) possible for the brain-absent infant; that we know....In the case of brain-absent infants, there is no *possibility* of awareness, the physical equipment being totally missing. Thus, in this narrow class of cases, there can be no question about possible human consciousness because it is a physiological impossibility, even during the few hours before brainstem activity also ceases.

On this third position, therefore, there are no intrinsic interests of anencephalics to be defended. It simply makes no sense to speak of them as though they were in any way like ordinary babies, although they are physiologically like human infants below the neck. Hence, it is correct to treat anencephalics as a class that is...unique...for which the determination of life or death need not be undertaken; it is a class for which we can say that, whatever else may be true of them, it is morally right that they be considered as suitable sources of life-saving organs.

Whatever the difficulties with

utilitarianism as a complete moral theory, the problem at hand is one in which a utilitarian analysis is wholly appropriate, and compelling in its result. The status of the anencephalic is such that there arises no conflict of rights. The overall gain in promoting transplants from anencephalics may prove to be very great. In the present state of the art, some doubts do remain; the rate and duration of success in such transplantation is unsure; the absolute number of successes is likely to remain small. In any given case, of course, transplantation would presuppose...that the parents of the anencephalic have given truly voluntary and fully informed consent for the donation, and that a suitable recipient for the donor organ is at hand. But these conditions are sometimes met. Parents sometimes desire intensely to advance such a donation, in order that some good may come out of their tragedy. It must also be the case, of course, that there is a potential infant beneficiary at hand, and that it will indeed die without the transplant. [T]hat is all too often true, because the demand for transplantable infant organs is growing while the supply of them (because of increasing prudence on the part of parents carrying infants in automobiles) is declining. From the donation of the organs, therefore, even when it is chancy, it is plain that all human parties concerned stand to receive great benefit. On the part of the brain-absent donor, there are no feelings, no sensitivities, no potentialities, no interests of any kind whatever; and therefore, one can be confident that no harm, no pain, no disadvantage of any kind is caused to it. When all of these conditions are met, as they sometimes are, one would need to be intoxicated by abstract principle to refuse to seek to do the good that can be done.

The possible objections to this third position, and the replies to those objections, deserve consideration:

1) *Objection.* Putting anencephalic infants in this special category, and taking their organs for others, is to treat them as mere means, rather than as ends-in-themselves.

Reply. This objection is based upon a conception of "end-in-itself"

derived from Kantian ethical theory, a conception that simply does not apply to the brain-absent infant. An autonomous moral agent, a rational human will, must not be treated merely as means, without regard to its own interests as end in itself. So Kant argued, and we may agree. But we know, with certainty, that the anencephalic neither is nor ever can be an autonomous moral agent or a rational will. Indeed, it cannot be an agent of any kind, or exhibit a will of any kind, or be anything even remotely like what may be fairly called an end-in-itself.

Of course the *parents* of the anencephalic are ends-in-themselves; their wishes must be respected, obviously, and every safeguard must be employed to ensure that they are not coerced or manipulated into giving their consent for the donation.

2) *Objection.* The third position invites abuse; it takes the first step down a slippery slope on which the descent may prove to be very speedy. What group comes next? Microcephalics? Hydrocephalics? The comatose? Those in persistent vegetative state? Once we violate the rule that organ donors must be dead, there is no telling what the end point will be.

Reply. The third position does not violate the rule that organ donors must be dead; it bypasses that rule, holding the normal determination of brain death to be not appropriate in this narrow category only. No other group, however severely limited their condition, is involved; no other kind of genetic anomaly can possibly be confused with those whose brains are missing. This third position is grounded upon the realization that anencephalics have an absolutely unique status, and must, in the interest of human decency and beneficence, be treated uniquely.

3) *Objection.* The third position requires an alteration of laws and principles that is purely *ad hoc*. But special exceptions so devised generally result in bad rule-making.

Reply. We accept the premise but reject the inference. The exceptional category advanced by the third position is "ad hoc." That is, it is addressed "to this case" and to this case alone. Rule-making that incor-

porates exceptions may sometimes be bad, because the exceptions specified lead to unjustifiable claims for other exceptions, and then to the breakdown of good principle. In this case, the exceptional category is so clear, so distinct from all other possible claims, and so plainly warranted by the medical realities, that to refrain from making this exception is to force under a general rule cases that ought to be distinguished. There are some occasions when good rule-making obliges us to recognize exceptional circumstances. This is one such occasion.

4) *Objection.* If we allow anencephalic infants to serve as sources of transplantable organs, the trust of the public in medical centers conducting organ transplantation will be undermined. That trust is precious, and essential for the general success of organ transplantation programs. The proposed change, therefore, will cause an overall reduction in organs donated, and a long-term decline in total human well-being.

Reply. This argument would have merit if its premises were true, but they are not. It is now plain that members of the public who attend to such matters very generally endorse the use of anencephalics as donors, and applaud and honor the parents of such newborns when they seek to recapture, by donation, some great good through their pain. The objection supposes a dull and unsympathetic citizenry; in fact, the distinctions and argument upon which this third position relies require only a basic understanding of what the absence of brain must mean. They gravely underestimate the general public who think them unable to appreciate, intellectually and emotionally, the significance of the special condition of anencephaly.

In fact, general public confidence is more likely to solidify and to grow if, over the long run, it becomes clear that in our medical centers judgments on these difficult matters are being made by sensitive and reasonable people, struggling to maximize the good of all parties while doing harm to none. It is precisely the over-rigid application of inappropriate rules to agonizing cases that gives rise to public puzzlement and distrust.

Conclusion

We conclude, all things considered, that this third position—establishing a special category for the infant born without a brain—is the position that ought to be generally adopted. Only in this way can we cut through the tangle to attend, quickly and with mercy, to the desperate needs of anguished parents and dying babies. We do not insist upon a change in the concept of brain death; we do not insist that the brain-absent infant should be treated as though it were somehow merely handicapped; we do not insist upon heroic, resuscitative treatments that would otherwise have been forgone for doomed anencephalics; we do not insist that old rules should be rigorously applied to new circumstances, or that all cases must be reduced to existing moral categories.

The third position, which we defend, looks toward a rethinking of the moral issues raised by the possibilities of organ transplantation, and provides a formulation of them in such a way that the life-saving transplantation of organs from anencephalics—intuitively thought right by virtually all of us—may be effectively defended in morals and in law.

This recommendation was approved 13 April 1988 by the members of the Ethics and Social Impact Committee, Transplant Policy Center:

Martin Benjamin, Gordon Burtch, Carl Cohen, Sandra Elfring, John Foglio, Eleanor Forlenza, Eugene Grochowski, Vivian Harrison, John Hardine, Victor M. Hawthorne, Marjean Howard, Shaké Ketefian, Jean Macklin, Rebecca Ramsdell, Jane Waskerwitz, Andrew Watson.

The proposal is that of the committee and is not an official position of the Transplant Policy Center.

Personhood Redux

by J.C. Willke and Dave Andrusko

It will come as no surprise to those who have observed or participated in the major bioethical debates of the past fifteen years that often contributors on all sides of an issue not only passionately disagree but seemingly talk past one another. Genuine debate is infrequently joined because advocates of a given proposal often resist the impulse of critics to explore both its probable and unanticipated consequences. Typically, advocates characterize their proposed change in the bioethical status quo as a commonsense accommodation to changing mores and advances in medical technology. They are not interested in "what-ifs," but want

debate on their recommendation limited strictly to its "merits."

By contrast, critics usually ask two related questions. First, how momentous—now and in the foreseeable future—will the impact of the contemplated change be on the immediately affected group, be that the unborn, disabled infants, or those in a persistent vegetative state? Second, is the reasoning used applicable to others, especially to broader categories of the medically dependent and disabled? Such questions require that the assumptions underlying a given proposal be spelled out if we are to know whether the requirements for inclusion under society's protective arm have been revamped. That is, are the qualifications for "personhood" being altered, and if so, at whose expense?

Proponents typically deny any broader implications, or deny that anyone can say what they will be. No

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