

The Living Code

Considering Organ Donation by Anencephalic Neonates

The history of the AMA's policy on anencephalic newborns as organ donors is a living example of what medical science can do sometimes conflicts with society's support or nonsupport of those possibilities.

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The AMA's *Code of Medical Ethics* – the living code

The mission of the AMA's 157-year-old *Code of Medical Ethics*—and its authors—is to set standards for the ethical and professional conduct of physicians within the ever-changing context of medical practice. There are at least 2 distinct aspects to the "context of medical practice"; one is the panoply of treatments and enhancements that medical science and biotechnology provide. These range from artificial life support and organ transplantation to in vitro fertilization and preimplantation genetic diagnosis. Such technologies change how we are born, how long we live, and how we die, and, in so doing, they place new demands on ethical decision making.

The second contextual component that the *Code* and its authors must consider is the environment in which physicians practice—society's understanding of emerging treatments and its inclination to accept or reject them as well as the system for the delivery and financing of medical care. Often these 2 components—what medical science can do and society's support or nonsupport of those possibilities—come into conflict. The conflict arises, for example, in legal arguments about withdrawal of life-sustaining treatment; public refusal to fund many forms of mental health treatment, and, to take the latest case, the debate over use of embryonic stem cells in research. Because of its contract with society, the medical profession must balance its interest in what science can do with what society is willing to support and fund. The *Code of Medical Ethics* sits at the fulcrum of this balancing act.

Reproductive medicine and neurology are often at the center of conflicts over treatments made possible by medical science and society's sense of how those treatments may support, challenge, or perhaps violate deeply held moral and social values. Between 1988 and 1995, the AMA's Council on Ethical and Judicial Affairs, stewards and authors of its *Code*, struggled along with society to balance the value of hope for organ recipients with the interests of anencephalic newborns, that is, infants born with no cerebral cortex.

The context for organ donation decisions

A convergence of medical trends set the context for this struggle. Ventilators prolonged the lives of those who could not breathe on their own; improved methods for artificial nutrition and hydration extended the lives of individuals with conditions that claimed their ability to swallow; advances in surgical techniques and immunosuppressant drugs contributed to the success of organ transplantation. And, confronted with the new circumstances in which individuals who could no longer breathe on their own could be "kept alive" mechanically, the medical profession and the US government undertook separate efforts to redefine "death" itself and the criteria for determining it. The Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death published its report in *JAMA* in 1968, proposing that death could be declared on the basis of irreversible cessation of brain function even while

ventilators might be maintaining respiration and circulation in the patient [1]. During the next 12 years, a good deal of confusion reigned concerning which criteria to use for determination of death—the Harvard report's neurological criteria, referred to in short as "brain death" by the profession and the public alike, or the previous standard which was irreversible cessation of circulatory and respiratory functions [2]. The President's Commission on the Uniform Determination of Death institutionalized the ambiguity rather than resolving it by simply adding the Harvard committee's neurological criteria for death to the existing standard and asserting in 1981 that death could be declared on the basis of either "(1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem" [3].

Thus, advances in medical technology and the policies that had sprung up to manage them set the stage for the Council on Ethical and Judicial Affairs' attention to organ donation by anencephalic neonates. Following successful transplants of the kidney, pancreas, liver, and heart in the late 1960s, the *Code* carried the AMA's first opinion on organ transplantation in its 1969 edition [4]. The 7-point "Guidelines for Organ Transplantation" emphasized that, though new, organ transplantation procedures were subject to all existing rules governing the patient-physician relationship; the prospect of donation was "no justification for a relaxation of the usual standard of medical care." Death of the donor, it continued, "shall have been determined by at least one physician other than the recipient's physician" and based upon "all available, currently accepted scientific tests" [5]. Though not stated explicitly in the *Code*, currently accepted scientific tests would have included neurological as well as cardio-pulmonary criteria in 1969. The 1969 *Code's* guidelines on organ donation have remained essentially the same over the years, even to the present.

Anencephalic Newborns as Organ Donors

In June 1988, 2 resolutions concerning organ donation were brought before the AMA House of Delegates and referred to the Council on Ethical and Judicial Affairs (CEJA) for investigation. One requested the AMA to reexamine the criteria used to select organ donors. The other sought ethical guidelines to address the use of prenatal diagnoses and organ "harvesting"; both concerned the transplantation of organs from anencephalic infants, some of whom were now able to survive for up to several days. The implicit question in the resolutions was this: Is it ethical to declare organ donor status for anencephalic newborns on the basis of prenatal diagnosis and, with parental consent, to procure the organs before the infant died of its neurologic devastation? In December 1988, CEJA reported its recommendation to the House of Delegates. The answer was, "No." Here are CEJA's words:

[CEJA] supports the voluntary donation of organs in appropriate circumstances. However, the Council does not view the use of organs of anencephalic newborns prior to a determination of death, ie, the complete and irreversible cessation of all brain function, as appropriate for transplantation purposes" [6].

The 1989 edition of the *Code* contained no separate entry on anencephalic neonates as organ donors.

The first separate opinion on anencephalic neonates as donors appeared in the 1992 edition, giving public voice to the view expressed in the 1988 report. The new opinion stated that the newborns could be kept on ventilators and provided other treatment to sustain "organ perfusion and viability until such time as a determination of death can be made in accordance with accepted medical standards and relevant law." The opinion went on to emphasize that retrieval of organs was "ethically permissible only after such a determination of death is made" [7].

By 1994, things had changed. In June 1994, "after more than a year of deliberation," the Council issued a lengthy report, a version of which was subsequently published in *JAMA* [8]. The extensively researched and documented report grounded its conclusions on 3 facts or assumptions: anencephalic newborns faced certain death, usually within 3 days; they lacked any degree of consciousness; and parents of such newborns often requested that their children's organs be donated. The Council reached the conclusion that, with prior consent of the newborn's parents, it was ethically acceptable to transplant the organs of anencephalic neonates without waiting for them to die naturally.

The 1994 report examined 5 objections to the policy it was proposing: (1) the new position violated the prohibition against removal of life-necessary organs from living persons, (2) the diagnosis of anencephaly might be incorrect, (3) the proposed practice could open the door to considering other living people as organ donors, eg, those in persistent vegetative states or the severely disabled, (4) the infrequency of cases in which anencephalic newborns could actually

be donors, and (5) anticipated harm to the public's trust in organ donation. The Council argued each of these points, some at great length. In each case, justification for permitting retrieval of organs from anencephalic newborns before they had been declared dead seemed to outweigh the arguments against doing so. The Council's recommendation was accepted by the House of Delegates and replaced the former opinion on organ donation by anencephalic neonates in the 1994 edition of the *Code*. After defining anencephaly, the new opinion stated:

It is ethically permissible to consider the anencephalic as a potential organ donor, although still alive under the current definition of death only if: (1) the diagnosis...is certain and confirmed by two physicians who are not part of the organ transplant team; (2) the parents of the infant desire to have the infant serve as an organ donor and indicate such in writing; and (3) there is compliance with the Council's Guidelines for the Transplantation of Organs [9].

The opinion went on to say that some parents who wished their anencephalic newborns to be donors might choose alternative means and "provide the infant with ventilator assistance and other medical therapies " to keep it alive until death was determined by current standards and relevant law [9]. Finally the opinion drew special attention to the fact that its new opinion marked a noteworthy exception to its guidelines on donation of organs necessary for life because these infants have "never experienced and will never experience consciousness" [9].

Reaction to the report and opinion was immediate, widespread, and highly critical. During the year following the opinion's release, the AMA and CEJA received protests from individual parents and physicians, advocacy groups such as the Anencephaly Research & Help Line, the American Association of Pro-Life Pediatricians, the Christian Medical and Dental Society, and medical specialty societies. And the Council became aware that its new opinion on anencephalic newborns as organ donors was incompatible with the policy of the United Network for Organ Sharing (UNOS), the organization established by the US Congress in 1984 to administer the nation's Organ Procurement and Transplantation Network. UNOS policy stipulates that organ procurement must occur after declaration of death by medical and legal standards.

The Council on Ethical and Judicial Affairs considered the clear message it had received from members of the profession and the public. Society was not about to tolerate alteration of principles derived from the closely held value it placed on the sanctity of life, no matter how damaged that life might be. If the owner of that life, himself or herself, vehemently refused treatment to sustain it, that was one thing, but others who had never known the will of the person in question should not end its life. In its December 1995 report entitled, "The Use of Anencephalic Neonates as Organ Donors—Reconsidered," the Council rescinded its 1994 opinion, pointing to concerns about accurate diagnosis of anencephaly and incomplete understanding of the possible level of consciousness in these newborns [10]. The report urged the scientific community to continue to investigate the consciousness of neonates and provide knowledge to guide future policy making on this topic. Promising to continue assessing relevant information, the Council recommended—and the House of Delegates approved—reinstating the 1992 opinion. Nearly a decade later, the 1992 opinion remains in the *Code*.

This history of the AMA *Code's* opinion on anencephalic newborns as organ donors is an "action shot" of the social contract and professional self-regulation. In this case, the message from the public and some members of the profession was that medicine had taken a step beyond the point to which society was willing to go. Upon reflection and renegotiation, the profession reassumed its former stance, one with which the entire profession and its contractual partner could agree.

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