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## Anencephalics and the AMA

by

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The Council on Ethical and Judicial Affairs of the American Medical Association has recommended that live anencephalic infants be approved as a "limited exception" to the general standard that donors of unpaired organs be legally dead. This recommendation should be recognized for what it is — a radical change in the current standard. The anencephalic infant is not born dead since it will be born with brain stem function. Anencephalic infants are born dying since they survive in utero as a result of maternal placental support. The proposal that anencephalics be declared "brain absent" and therefore an exception to the Uniform Determination of Death Act<sup>1</sup> is a subterfuge concocted out of a pragmatic desire to increase the supply of donor organs in the perinatal period. It has been estimated that the number of infants who could conceivably be benefited by transplantation of the heart, liver, or kidney who are born in the country annually would be approximately 2000 (500 hearts, 500 kidneys, 1000 livers).<sup>2</sup> Because of various logistic problems in organ procurement, however, it has been estimated that, *at most*, 25 kidneys, 12 hearts and 7 livers could be harvested from anencephalics annually.<sup>3</sup> This relatively meager projected benefit hardly justifies sweeping changes in the law and bioethics. Changing laws to declare anencephalics dead would inevitably place in jeopardy those whose situation is identical on the relevant criteria i.e. the comatose patients who possess brain stem function but are alleged to lack higher cortical function.

The Council's recommendations include the criterion that the diagnosis of anencephaly be "Certain". During the period when Loma Linda University was conducting a program to salvage organs from anencephalic infants, almost a third of the infants referred to the program as anencephalics were incorrectly diagnosed and actually had other non-life threatening central nervous system anomalies.<sup>4</sup>

The experience at Loma Linda is particularly instructive.<sup>5</sup> The protocol at Loma Linda provided for two different managements. The first six infants were placed on respiratory support at birth. The second set of infants were placed on ventilator support only when respirations or heart rate slowed. Respirator

support was continued for a maximum of seven days. Of the twelve infants only two were declared dead on the basis of irreversible cessation of brain function, including brain stem, within the seven day limit. One of these infants had a viable heart and liver but no suitable recipient could be found. The experimental protocol has now been abandoned with no plans to renew it. The institution's Chief of Neonatology declared that the program had "failed miserably" that it was a "misuse of health care resources". Their further judgement was that "the slippery slope is real" and that "the ethical qualms of critics have often proven true."<sup>6</sup> There is no basis for optimism that a repeat of the Loma Linda protocol would be any less disastrous.

Ethical rationales for approving the taking of organs from live anencephalic donors are usually based on utilitarian grounds. The donors' lack of consciousness is usually used as the basis for sacrificing the life of the anencephalic in order to save the life of another infant. Killing one patient to benefit another is a line that the Society should not cross. Transplantation programs have always scrupulously avoided the appearance of vested interest and impropriety by having the caretakers declaring death in the donor completely separate from the transplant team. The AMA Council's opinion attempts to circumvent this principle by having the diagnosis of anencephaly considered to be tantamount to a declaration of death.

What is done for the anencephalic infant should be in the best interest of the anencephalic infant. The interests of society and/or parents should be secondary. The fact that the infant suffers from a major congenital anomaly and an absence of cortical function does not disqualify it from an entitlement to justice in health care.

The anencephalic infant should be allowed to live out its inevitably brief life span with comfort care and a minimum of technological intervention. Artificial prolongation of life in order to qualify the infant as an organ donor is misguided and inappropriate. Although there is a temptation to provide some sort of consolation for grieving parents, it should not be accomplished at the expense of an injustice to the child.

Attempts to implement programs to take organs from live anencephalic donors have had predictable adverse effects on physicians, nurses, and other health care personnel at the cribside. In addition, the cynicism implied in the attempt to create a loophole for the use of live donors has resulted in a crisis of confidence and a loss of public trust in the whole system of organ donation and transplantation.<sup>7</sup>

The AMA Council on Ethical and Judicial Affairs should reevaluate its opinion in light of potentially catastrophic ethical, legal, and public policy consequences.

— Eugene F. Diamond, M.D.

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