Anencephalic Infants as Potential Organ Sources: Ethical and Legal Issues

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June, 1989

“Baby Gabrielle,” born October 12, 1987, with a fatal condition diagnosed prenatally as anencephaly, was brought to the Children’s Hospital in London, where she was placed on a respirator. Her parents had asked that she be connected to the machine so that her organs might be kept viable for donation to a critically ill infant in need. Baby Gabrielle was declared brain dead on October 14, 1987. Her body, still attached to the respirator, was flown to Loma Linda University Center in Loma Linda, California. On October 16, her heart was transplanted into a baby, Paul Holc, who had been delivered that day by caesarean section to receive the transplant. (See citations 47-52).

Since the successful transplant of Baby Gabrielle’s heart, other parents have asked that their infants, diagnosed prenatally as anencephalic, be placed on respirators after birth so that their organs may be donated. However, many problems have been encountered: some anencephalics have been stillborn; others, considered to be possible organ sources, had not met the brain death criteria after seven days on the respirator and were removed from the respirator to die a natural death; still others had to be removed from the respirator because, despite the apparently great need for organs, no recipient was found that “matched” the donor organ (49-52). Indeed, these difficulties, coupled with the ethical debate that such procedures had aroused, caused Dr. Leonard Bailey of the Loma Linda University Medical Center to announce in August, 1988, the suspension of all such transplants, in order to allow Loma Linda time to reassess its approach (30).

Today, several types of organ transplantation have become standard and accepted practice in medicine, although the high cost of most kinds of transplants has occasioned debate about the relative priority that this technology should receive in the health care system. However, the demand for organs greatly exceeds the supply, and nowhere more poignantly than in the need for small organs to be transplanted into critically ill infants. According to some estimates, approximately 400-500 infant hearts and kidneys and 500-1,000 infant livers are needed in the U.S. each year (4)(15)(32). Moreover, it has been asserted that 40-70% of children under two years of age who are on transplant waiting lists die before donors can be found (15)(8). Some suggest that anencephalic infants could serve as much-needed organ sources. [The term “sources” is used rather than “donors”, since infants cannot “give” their organs].
What Is Anencephaly?

Anencephaly, one of the most serious neural tube defects, is an incurable, fatal condition. Statistics of the number of anencephalic infants born in the United States each year vary. Some estimate that 2,000-3,000 anencephalic infants (one of every 1,800 births) are born each year (6)(47). Others provide a more conservative estimate: approximately 1125 anencephalic infants born each year (19). It has been estimated that 25-45% of anencephalic infants are born alive and that approximately 95% of these die in the first week of life (35)(13). However, it has also been argued that there are notable documented cases of anencephalic infants surviving up to 16 days and even 14 months (19). Anencephaly is characterized by a lack of brain development above the level of the brain stem. The cerebrum, the cerebellum, and often the bones of the skull are absent. However, there is still brain stem activity, which enables the heart and lung to function for a short time. As noted above, many anencephalic infants are stillborn, but those who are not can maintain vital functions for only several hours to several days (or, more rarely, weeks), developing less and less regular breathing, and eventually dying of respiratory failure. Theoretically, mechanical ventilation could be used to prolong the lives of these infants, but the ventilator is not routinely used because it would merely delay an inevitable, early death. However, if anencephalic infants were to be used as organ sources, they would have to be placed on life-support machines to assure continued viability of their organs until, under current law, they could be declared brain dead.

Anencephaly can be diagnosed prenatally with a high degree of certainty (35). The initial screen for anencephaly and other neural tube defects is performed by testing for high levels of maternal serum alpha-fetoprotein in the second trimester of pregnancy (45), and by ultrasonography in the third trimester of pregnancy. A confirmed positive diagnosis may lead some to consider second trimester abortion, or even third trimester abortion. It has been noted that approximately 20% of pregnancies in the United States are screened for neural tube defects, and 95% of detected anencephalic fetuses are electively aborted (19). Given the fatal outcome of the condition, even third trimester abortions are considered by some to be ethically acceptable (27), and are thought by one author to be legal in about half of the 50 states (13).

The Anencephalic Infant as Organ Source

Many medical, legal, and ethical questions are raised by the potential use of anencephalic infants as organ sources. The positions that one adopts on this question can vary greatly, depending upon one’s convictions on such issues as abortion, eugenics, fetal rights, rights of handicapped newborns, the definition of death, and one’s conception of what constitutes personhood. Two of these related issues are particularly pertinent and therefore important to explore in depth: the criteria used for the determination of brain death and the concept of “personhood.” Are anencephalic infants being considered as potential organ sources because they are dead, because they will die imminently and inevitably, or because their brains have not yet developed, and never will develop, to a stage at which they can be considered “human persons”? To which of these alternatives is ethical justification of or opposition to the use of anencephalic infants as organ sources directed? This Scope Note does not attempt to provide a full examination of these two important related issues because of the extensive amount of material written on each of these subjects. However, the reader is encouraged to examine each of them, for they are essential to a more complete understanding of the question at hand. A list of additional reading material on these subjects is found at the end of this Scope Note. While by no means exhaustive, this list contains several of the articles on these subjects most frequently cited in the literature.

Medical Questions

What, then, are some of the medical questions that must also be resolved even as ethical questions are being addressed? First, there is disagreement about the accuracy of the diagnosis of anencephaly. Some, such as Caplan (5), are convinced of its 100% accuracy. Others, like Shewmon, Capron and others (18)(19), are more cautious. One may ask whether anencephaly is clinically distinguishable from other abnormalities...
with certainty. If not, are there grounds for fears that in years ahead other less severely handicapped newborns could also be seen as potential organ sources? Secondly, there is a series of questions revolving around the difficulty of determining death in infants less than seven days old. Guidelines for the determination of brain death issued by the Task Force for the Determination of Brain Death in Children and endorsed by the American Academy of Neurology, the American Academy of Pediatrics, the American Neurological Association and the Child Neurology Society, are applicable only to infants seven days old and older, and many brain death guidelines acknowledge the difficulty of applying such criteria to infants in the first week of life (20)(56). Thus, no generally-accepted criteria have been developed that would apply to anencephalic infants under the age of seven days. Third, there are questions raised by the difficulties encountered in matching donors and recipients for organ transplantation. Is pediatric transplantation sufficiently efficacious to justify seeking anencephalic infants as organ sources? Or are there so many obstacles to matching donors and recipients, especially in pediatric organ transplantation, that this is an unwise and unnecessary course upon which to embark (19)?

Legal Issues

Legal questions center around the applicability, to the question at hand, of state laws patterned after two model statutes — the Uniform Definition of Death Act (UDDA) and the Uniform Anatomical Gift Act (UAGA). Almost all states as well as the District of Columbia have adopted either UDDA laws or some legal form of brain-related death, and all 50 states and the District of Columbia have adopted UAGA laws (16)(36)(61). Under the UDDA, death is defined as either “irreversible cessation of circulatory and respiratory functions” or “irreversible cessation of all functions of the entire brain, including the brain stem” (65). Among the topics delineated in the UAGA are the request for consent required prior to an anatomical gift, and the manner of executing anatomical gifts (71).

By UDDA brain death criteria, anencephalic infants are not dead, because there is some brain activity in the brain stem, which controls respiration and heartbeat. However, if one were to wait for the cessation of all brain activity before removing organs, the organs would be severely damaged and unsuitable for transplantation. Should brain death and/or organ donation laws be changed? Two state bills have responded to this question: California Senate Bill 2018, introduced on February 19, 1986, by Senator Milton Marks, proposed to amend the UDDA to define anencephalic infants as already dead, while New Jersey Assembly Bill 3367, introduced by Assemblyman Walter Kern, Jr., on October 27, 1986, proposed to allow anencephalic infants to be organ sources even if they are not dead.

Ethical Dilemmas

The ethical dilemmas posed by the potential use of anencephalic infants as organ sources are complex and intricately intertwined with corresponding medical and legal issues. In fact, the complexity of issues surrounding the question at hand have prompted some to insist on the need for careful discussion and debate (17), while others have even called for a moratorium on transplants from anencephalic infants until the many complex issues can be debated (14). Across the country, within professional societies and in hospital settings, many task forces on the use of anencephalic infants as organ sources are focusing their attention on this question.

On the general question of using organs from anencephalic infants two major ethical positions have been advocated. The one places emphasis on the benefits to be gained from such a practice, while the other emphasizes the need for respecting human beings. Those who maintain that the use of anencephalic infants as organ sources is morally justifiable highlight the need to maximize benefits, and point both to the benefit to the grieving parents and the benefit to society that such an action achieves. They underscore the necessity of providing an opportunity for grieving parents to find meaning in a tragic situation, and insist on the critical role anencephalic infants can play in providing a remedy to the acute shortage of much-needed pediatric organs (16)(21)(22). On the other hand, those who maintain that the use of anencephalic infants as organ sources is morally unjustifiable argue that anencephalic infants cannot be used solely as a source of organs...
for other children. They refer to the Kantian principle that a human being must never be used solely as a means towards an end, as contrasted with utilitarian principles of maximizing benefits (4) (7) (11) (19).

Even if the use of organs from anencephalic infants is found to be morally justifiable, certain procedural questions remain. The first concerns the solicitation of consent. What procedures will ensure truly voluntary informed consent? Secondly, many authors (9)(35)(13) highlight the importance of separating roles in order to avoid conflict of interest. They find it essential that no member of the transplant team be involved in the diagnosis of anencephaly or in the determination of brain death.

There are also ethical dilemmas surrounding the decisions to be made following prenatal diagnosis of the condition of anencephaly (45). Some argue that abortion is morally unjustifiable, even in these circumstances. Others (27) find that in some situations, including prenatal diagnosis of anencephaly, termination of pregnancy even during the third trimester can be morally justifiable.

In this connection, the question of personhood has arisen, with some Kantians asserting that only persons need to be respected. The question then arises: Do anencephalic infants possess the necessary characteristics to be designated as persons? To this question several answers have been proposed. Some state emphatically that “anencephalics never had and cannot develop any semblance of personhood” (6) or that anencephalic infants are human biologically but are not persons (45). A second group, although supporting organ retrieval from living anencephalic infants, maintains nonetheless that they are persons deserving of due respect (15). Some argue further that the anencephalic infant’s status as a person constitutes grounds for judging organ retrieval from a living anencephalic to be morally unjustifiable (72).

In the midst of a very complex debate, there seem to be emerging, in the literature on the use of anencephalic infants as organ sources, three possible policy options. One option would be to accept as legally binding the criteria for determination of death as delineated in the UDDA, recognize that anencephalic infants are by such standards living, and declare transplantation of organs from anencephalic infants to be unacceptable (2)(7)(21). The second option would be to amend the UDDA, so that some or all anencephalic infants who still have some brain-stem activity would be considered dead and the transplantation of their organs would be legally permissible (6). The third option would be to retain the definition of death as contained in the UDDA, but modify instead the UAGA to permit procuring organs from some living anencephalic infants (5)(6).

Primary Documents to Consult


A detailed account of the case of Baby Gabrielle is presented in this article. The positions expressed prior to that transplant at the January 1987 international gathering of experts in Canada on the question of using anencephalic infants as organ sources are summarized, and the new directions in which they have led Canadian researchers are also described. Key ethical questions are raised and analyzed.


The authors of this critique firmly assert that allowing anencephalic infants to be used as organ sources is not morally acceptable. They refute the “brain-absent theory” by challenging its proponents to take seriously the matter of respect for the personhood of anencephalic infants, and they affirm the necessity of abiding by strict criteria for whole brain death.


The surgeon at Loma Linda University Medical Center who performed several transplants from anencephalic infants, including that of Baby Gabrielle, shares his perspective on the use of anencephalic infants as organ sources, outlines his moral reasoning, and answers questions.


This comprehensive article examines the question at hand from the technical viewpoint (supply and demand of pediatric organs) as well as from the legal and ethical viewpoints. The latter discussion focuses on the moral significance attributed to brainstem activity and the question of whether the termination of the brief lives of anencephalic infants for the good of others can be justified. Reference is made to the reports of various national commissions. The author concludes that “a heavy burden of proof should lie with those who advocate a change in our current legal and ethical standards.”


Following a discussion of various factors contributing to the concern manifested over the use of anencephalic infants as organ sources, the author questions why, as in other situations, it would not be acceptable for anencephalic infants to be living “donors”. He finds unnecessary the emphasis placed on issues such as the determination of death criteria, and argues that the diagnosis of anencephaly is far more accurate than the determination of brain death in young children. He thus calls for a modification of current laws to permit organ donation from either those meeting brain death criteria or those diagnosed as anencephalic.


Many fundamental issues are raised and discussed in depth in this comprehensive analysis of the use of anencephalic infants as organ sources. The author examines in turn the potential benefits of using anencephalic infants as sources and the objections to such a practice. Caplan concludes that anencephalic infants, abortuses and brain dead infants should be used as organ and tissue sources, and that laws and public policy should be changed to allow this practice.


Capron discusses the significant problems with and undesirable consequences of amending the UDDA as well as the UAGA in order to allow anencephalic infants to be used as organ sources. After a thorough examination of major ethical issues, he concludes that anencephalic infants should not be sacrificed for the good of those in need of transplanted organs.


A comprehensive analysis of the medical, legal and ethical issues surrounding the use of anencephalic infants as organ sources is provided here. This includes a detailed discussion of the relevance of such related issues as determination of death criteria, the moral status of an anencephalic infant, and the moral justifiability of abortion. The authors conclude that brain-death criteria should be re-examined and that the use of anencephalic infants as organ sources “is not a violation of personal dignity.”


The Working Party affirms that the absence of the forebrain in anencephalic infants together with apnea shall be recognized as death. They conclude that organs for transplantation may be
removed from anencephalic infants when two doctors who are not members of a transplant team agree that spontaneous respiration has ceased.


In this comprehensive analysis of the subject, the authors call for clarification of the medical facts and moral-legal issues raised by the use of anencephalic infants as organ sources. They delineate arguments favoring anencephalic infants as organ sources, as well as raising concerns and questions. Recommendations proposed include the importance of engaging a full-fledged public debate on the subject, and the importance of considering related moral dilemmas such as the status of permanently unconscious patients.


The author, organizer of the Handicap Division of the Society for the Protection of Unborn Children, identifies and examines four basic questions which must be addressed before reaching a decision as to whether anencephalic infants can be used as organ sources: what constitutes a human being, what constitutes a person, what definition of death is being used, and what rights belong to human beings or persons. The author concludes that it is unethical to use the organs of anencephalic infants for transplants.


A case history serves as the basis for examining legal and ethical questions faced by nurses in neonatal intensive care units when an anencephalic infant is being considered as a potential organ source. Key ethical questions are discussed: criteria for brain death, the definition of personhood, and the need to balance risks and benefits. Finally, the authors examine the obligations of nurses — to the infant, parents, society, and themselves.


The greater part of this lengthy, comprehensive article is devoted to the ethical and legal issues raised by the consideration of anencephalic infants as potential organ sources, and to the presentation of an ethical justification for the retrieval of organs from anencephalic infants. The authors examine, in turn, organ retrieval before total brain death and organ retrieval from brain dead anencephalic infants. They maintain that society is more open to preserving the organs of an anencephalic infant for transplantation (even if it hastens death) than to redefining death to include anencephalic infants.


The complex intertwining of medical, ethical, and legal questions surrounding procedures used to transplant organs from anencephalic infants is clearly highlighted in this article. The author focuses on the centrality of the issue of determining and/or redefining death in anencephalic infants. He concludes by calling for a moratorium on transplantations from anencephalic infants “while we gather facts, debate the reasons, and develop consensus.”


After examining the technical feasibility as well as the risks and benefits of a need for fetal organ transplantation, the author focuses on ethical and legal issues. Harrison rejects the definition of anencephalic infants as lacking personhood and proposes to view anencephalic infants as dying persons characterized by brain absence, a condition he believes should be
16. Loma Linda University Medical Center. Anencephalic Organ Donation Committee. Considerations of anencephalic infants as organ donors: a working document. Available from: David Larson, Ph.D., Director, Ethics Center, Loma Linda University Medical Center, Loma Linda, CA 92354, 18 December 1987. 14 p.

This outline and justification of Loma Linda’s protocol for organ retrieval from anencephalic infants details legal, medical, and ethical considerations, including parental decision-making as well as the importance of actions initiated for the anticipated benefit of others. Six appendices accompany the document, including the parental consent form in use at Loma Linda.


This well-documented article presents an excellent overview of the history of the actual use of anencephalic infants as organ sources. After highlighting the controversy raised by recent cases at Loma Linda University Medical Center and related legislative proposals, the authors proceed to review in detail actual clinical accounts in the medical literature of the use of anencephalic infants as organ sources from 1966 to the present (at least 32 cases in total for kidney donation alone). They conclude by tracing the discussion of ethical and legal aspects of this practice as it has developed since 1987.


A detailed description of the clinical condition of anencephaly is provided. Many medical facts and uncertainties relevant to the ethical and legal dilemmas surrounding the use of anencephalic infants as pediatric organ sources are highlighted. Statistics presented lead the author to assert that the total number of infants likely to benefit from anencephalic organs is so small that one should hesitate before revising brain death criteria. Many references are cited.


In this comprehensive article complete with extensive references, the authors argue that proposals to use anencephalic infants as organ sources present both practical and ethical problems. They refute in detail the four possible ways in which this practice could be made legal, and conclude not only that such proposals are shortsighted, but that “the moral confusion unwittingly introduced into society would constitute a far greater evil than the good done to the relatively few surviving recipients of these organs.”


These guidelines set forth historical criteria, physical examination criteria and laboratory testing methods necessary for accurate determination of brain death in children. They also include recommended observation periods for this determination, which vary with the age of the patient. It is stated clearly that the criteria cannot be applied for infants less than seven days old.


The policy recommendations of the Committee, ratified in April 1988, are summarized here. The Committee considers that anencephalic infants should be treated as a class of living infants that is unique, “for which the determination of death need not be undertaken” prior to organ transplantation. They affirm that “it is permissible, with the fully informed and freely given consent of the parents, to remove [anencephalics’] organs for transplantation.” Responses are provided for four possible objections to this position.

The authors of this article explore three levels of justification for Loma Linda’s protocol to meet the severe shortage of pediatric organs by attaching anencephalic infants to respirators until brain death criteria are met. Ethical issues are examined in the context of both a deontological-based ethic and a utilitarian-based ethic. Important factors relevant to the medical issue of the determination of brain death are discussed in detail. The article also includes excerpts from Loma Linda University’s “Protocol on Anencephalic Infants as Organ Donors.”


This article presents an overview of various ethical and legal dilemmas raised by the use of anencephalic infants as organ sources by summarizing arguments put forth in some of the early most frequently cited articles in the literature.

Other Documents

Journal Articles and Reports


News Articles


55. Rothenberg, Leslie S.; Shewmon, D. Alan; and Walters, James W. Anencephalic infants: means to an end or ends in themselves? Los Angeles Times, 10 December 1987, Part II, p. 11.

Additional Readings on Brain Death and Personhood


SCOPE NOTE 12 was prepared by Sue A. Meinke, who is research assistant at the National Reference Center for Bioethics Literature.

This publication is supported by funds provided under Grant Number LM04492 from the National Library of Medicine, National Institutes of Health.

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