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## **Anencephalic Infants as Donors for Organ Transplantation**

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*The Thomas Linacre Institute of Christian Ethics is "a clinically based ethical voice which can combine the rich Hippocratic insights with the added dimension of papal pronouncements." It is seen as a need by the National Federation whose broad and medically sophisticated membership is relied upon to develop policies and position statements, reinforced by theologians, philosophers, ethicists and other professionals "who share our commitment to orthodoxy".*

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The success rate in human transplantation has improved dramatically with the widespread availability and use of cyclosporine A to control the rejection phenomenon.<sup>1</sup> Until recently, transplantation procedures in newborn infants have been largely unsuccessful because of technical problems unique to the age group. However, some centers are now reporting acceptable success rates in cardiac transplantation in the perinatal period.<sup>2</sup> It has been estimated that 10% of the 28,000 infants born in this country with congenital heart disease will have lesions not correctable by current surgical techniques, the most significant being by hypoplastic left heart syndrome and fibroelastosis.<sup>3</sup> In addition to infants born with congenital heart disease, other irremediable conditions such as renal agenesis and atresia of the bile ducts might be benefitted by transplantation of the kidney and liver, respectively.<sup>4</sup> It has been estimated that the number of infants who could *conceivably* be benefitted by transplantation of the heart, liver, or kidney who are born in this country annually would be approximately 2,000 (500 hearts, 500 kidneys, 1,000 livers).<sup>5</sup>

With the development of drugs to control rejection, the most significant limiting factor has become the shortfall in the number of organs available for transplantation. Organs for transplantation must be of the appropriate

size for the age group. The adult donor pool is largely drawn from otherwise healthy persons who die as the result of acute trauma sustained in auto accidents or motorcycle accidents. Newborn infants, obviously, seldom die from such causes and suitable donors for organs in this age group are in short supply.<sup>6</sup> Out of frustration from the shortage of donor organs, surgeons in Germany, Japan and Holland turned to a population of infants who are born dying, but whose organs, aside from the brain, may be transplantable.<sup>7</sup> Anencephaly occurs in approximately 0.31 of every 1,000 births, liveborn and stillborn, in the United States.<sup>8</sup> Anencephalics have been targeted for use in questionable human experimentation in the past and have been considered by medical opportunists as subjects for exploration.<sup>9</sup> Heretofore, anencephalic infants have not been resuscitated and have been allowed to live out the inevitably brief period before their demise without intervention by ventilators or other life support technology. It has been proposed, however, that anencephalic infants be qualified as organ donors by declaring them to be "brain absent" and, therefore, dead.<sup>10</sup> This would allow the immediate harvesting of organs to avoid the deterioration of organs that would ensue if the infant were allowed to die naturally through a gradual process of asphyxiation and organ failure.<sup>11</sup>

### **Legislative Measures**

Although the concept of declaring the anencephalic infant dead as a result of its being born "brain absent" was first proposed in this country by Harrison,<sup>12</sup> it had previously been established in the Federal Republic of Germany. In 1980, Beller and Quakernach<sup>13</sup> proposed that the absence of the brain in anencephaly be considered the equivalent of destruction of the brain by trauma. The concept that the infant has never been alive, even though his heart may be beating, is accepted by the courts in West Germany and kidney transplantation from anencephalic donors has been reported from that country.<sup>14,15</sup> Bills to legalize the declaration of death by virtue of "absence of the brain" have been introduced in this country in at least three states, California, Ohio, and New Jersey.<sup>16</sup>

Legislation usually follows one of two strategies: 1) to modify the statutory standards for determining human death set forth in the Uniform Determination of Death Act (UDDA) or 2) to permit the patients to donate the child's organs even though the child does not qualify as a donor under the requirements set forth in the Uniform Anatomical Gift Act (UAGA) i.e., that organs may be removed only after a physician not involved in the transplant procedure determines that the organ donor has died.

### **Medical Issues**

The number of infants who have had a successful transplantation is limited and there has not been an opportunity for long range followup.

Although the doses of cyclosporine used are small, long term immunosuppression does carry a price.<sup>17</sup> The effects on growth, renal function, lymphatic tissue and bone marrow suppression are important concerns. The economics of long-term laboratory surveillance and expensive drug therapy are formidable. Anencephalic infants are not born dead, although they may be considered as dying. They survive in utero as a result of maternal placental support, but birth guarantees death. They do not necessarily die quickly. A recent study indicated that 40% lived longer than 24 hours, 35% will still be alive on the third day and 5% on the seventh day.<sup>18</sup> One infant survived 14 days. There are other infants with severe neurological abnormalities (hydranencephaly, microcephaly, holoprosencephaly) who also have a prognosis for limited survival. They, like the anencephalics, will still have central nervous system functions, particularly at the level of the brain stem. Declaring severely defective infants "dead" on the basis of absent higher brain functions obviously prepares us for the declaration of death for those who are permanently comatose and therefore display none of the higher cortical functions. As Capron<sup>19</sup> has pointed out, the use of the term "brain death" to describe newer standards for determining death only adds to the confusion. This terminology suggests that organs rather than persons die and that there are several kinds of death depending on the organ involved. The truth is that death is a unitary concept that can be determined by several standards, each appropriate under particular circumstances. It is also pertinent to remember that only a small percentage of patients declared dead on the basis of cessation of total brain function are candidates for organ donation.<sup>20</sup>

The protocol at Loma Linda for the preservation of donor organs from anencephalic children, involved deviations from the standard practice of allowing anencephalics to die with comfort care and minimal intrusion. According to Peabody, the first six infants entered into the protocol were placed on respiratory support after birth.<sup>21</sup> This appeared to prolong brain stem function and to delay a declaration of death, even as it preserved potential donor organs. The second set of six infants underwent a change in procedure whereby infants were placed on the respirator only when respiration or heart rate slowed substantially. Respiratory support was continued for a maximum of seven days. Of the 12 infants, brain death was declared within the seven day limit in only two. One infant who appeared to be a suitable donor candidate was disqualified when a physician attending the infant "started to cry and became very uncomfortable with the experience." It has been part of the protocol that the procedure would be terminated at the point where it was not acceptable to the entire staff. The second infant was felt to have a viable heart and liver for donation, but no suitable recipient could be found. This points up a quandary inherent in newborn transplantation. Although the shortage of donor organs is bonafide, the logistics of availability inevitably create situations where organs may be available when no recipient is waiting and vice-versa.

Infants with hypoplastic left heart or fibroelastosis have a very short life expectancy, unlike adult candidates for transplantation who frequently have cardiomyopathies compatible with longer survival in anticipation of donor organ availability. Some adults may be put on mechanical assist devices to prolong further their ability to survive a wait for a match. Although Dr. Calvin Stiller, chief of the Multi-Organ Transplant Service at University Hospital in London, Ontario, states that "Baby Gabrielle", the anencephalic donor of a heart used for transplantation at Loma Linda, met all the guidelines for declaring brain death in children as formulated by a joint task force of the American Academy of Neurology, American Academy of Pediatrics and the Child Neurology Society, others disagree. As pointed out by Shewmon, "The guidelines do not recognize our ability to diagnose brain death reliably in anybody less than seven days of age".<sup>22</sup> In a scholarly and comprehensive review of the medical aspects of anencephaly, Shewmon has pointed out the numerous logistic pitfalls in the harvesting of organs from anencephalics.<sup>23</sup> He estimates that, at most, 25 kidneys, 12 hearts and 7 livers could be used annually. Such a meager projected benefit hardly justifies sweeping changes in the law and bioethics.

The Loma Linda experimental protocol has now been abandoned, according to the institution's Chief of Neonatology.<sup>24</sup> Conceding that their plans to harvest organs from brain defective babies have "failed dismally" and that "The ethical qualms of critics have often proven true", the Loma Linda officials have suspended the program with no plans of reconstructing it in the immediate future. The program was judged to be a "misuse of health care resources" by its directors. Dr. Joyce Peabody admitted that the program was compromising the dignity of the deformed children (one anencephalic infant had been kept alive for four months) and that she had become convinced that "the slippery slope is real". The center vowed to continue to use more acceptable means to make organs available "for the 40 - 70% of infants who die waiting for organs". Anencephalic donor programs continue in Holland, Japan and West Germany.

### **Legal Issues**

The Uniform Determination of Death Act has been adopted in 42 states and the Uniform Anatomical Gift Act has been adopted in all 50 states. The former (UDDA) is based largely on the attempt by the Presidential Commission for the Study of Ethical Problems in Medicine to clarify the definition of death and to develop standards for the determination of death at the bedside. The Uniform Determination of Death Act defines death as 1) the irreversible cessation of circulatory and respiratory function or 2) the irreversible cessation of all functions of the brain including the brain stem. Liveborn anencephalic infants have at least transitory brainstem function and are, therefore, not qualified as organ donors under the UAGA because they are not dead by the standards of the

UDDA. As pointed out by Capron, adding those, like anencephalics, who possess brain stem function to the category of dead persons would be a radical change.<sup>25</sup> Anencephalics are not dead, but dying. They are alive and breathing and this fact is obvious both to the attending physicians and family. The importance of brainstem function is that 1) it serves as the principal source of integration for vital physiological processes and 2) it produces sufficient activity in the individual to support the appearance of life by our basic, intuitive criteria.<sup>26</sup> The fact that there is a prognosis for the inevitable loss of these functions in the short term did not enter into any of the calculations of the Presidential Commission in reaching its consensus on defining death. Harrison has suggested that "brain absent" be given the same legal status as brain death.<sup>27</sup> He might be encouraged in his calculus by some parents who would see organ donation as a positive outcome for the otherwise tragic occurrence of anencephaly.<sup>28</sup> The effect on health care personnel would be predictably adverse, however, since obviously alive infants would be declared dead by a pretext.<sup>29</sup> It may be that the overall effect on transplantation programs would be to reduce rather than increase the availability of organs for transplant based on a backlash produced in both the public and the profession.<sup>30</sup> Changing laws to declare anencephalics dead would inevitably place in jeopardy those whose situation is identical on the relevant criteria, i.e., the permanently comatose who possess brain stem function, but are alleged to lack higher cortical functions. These patients who have spontaneous breathing and heartbeat, sleep-wake cycles, eye movements, yawning and other reflex activity are not dead or even imminently dying, providing they are given basic care including food and drink.

### **Philosophical Approaches**

One approach to the question has been the utilitarian calculation in which the greatest good for the greatest number is achieved by accepting a "small" injustice done to the anencephalic child (who will die quickly anyway and lacks capacity for rational thought) in return for the greater good of saving the lives of otherwise doomed transplant recipients. Proponents of allowing organs to be taken from anencephalics who use this rationale include Caplan and Fleischman.<sup>31</sup> A variation on this philosophical rationale is the so-called Social Contract Theory of Rawls in which the decision-maker is unbiased because he is oblivious of which role he plays (parent, organ recipient, anencephalic donor or attending physician). Thus unbiased, he aims at the outcome which would avoid the worst scenario, which would presumably be that of a patient in need of an organ with no donor available. It would be alleged that if the anencephalic could reflect on his plight, he would consent to organ donation since his future is hopeless with or without the organs in question.<sup>32</sup>

Kantian philosophy, on the other hand, would state the imperative that no human person should be treated merely as means to an end.<sup>33</sup> The



anencephalic is used as a means to the desirable end of saving another child's life. The tendency on the part of our society has been to declare that some human beings are non-persons who may be used as means. The fetus is a "non-person" who can be sacrificed in abortion for material ends or for societal ends in the case of fetal experimentation. The defective retarded newborn or the comatose adult may be declared non-persons on the basis of dubious standards such as a lack of "cognitive or affective" function<sup>34</sup> or "relational potential".<sup>35</sup> Our society has had little difficulty in defining certain human beings out of existence as persons.<sup>36</sup>

Anencephaly has been proposed as justification for the performance of abortion in the third trimester.<sup>37</sup> It is difficult to propose that killing the anencephalic one day before delivery is justifiable, but that killing him for his organs one day after delivery is unethical. Very little is known about neurological function in anencephalics, however. They are apparently functionally closer to normal newborns than they are to adults in chronic vegetative states.<sup>38</sup>

### **Catholic Teachings**

Catholic medical teachings address themselves to the intrinsic rightness or wrongness of actions more so than their consequences. Judeo-Christian tradition asserts the sacredness of human life made in the image and likeness of God and a prohibition against the direct taking of innocent human life irrespective of alleged benefits to others. We are enjoined to "love persons and use things and not to love things and use persons".<sup>39</sup> As clearly stated by the Second Vatican Council, Catholic teaching is that "God, The Lord of Life has entrusted to human beings the noble mission of safeguarding life — abortion and infanticide are nefarious crimes" ("Gaudium et Spes" No. 51).

The recent document of the Vatican Congregation for the Doctrine of the Faith (Feb. 22, 1987), entitled "Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation" promulgates the same teaching as follows: "Thus, the fruit of human generation from the first moment of its existence, that is to say from the moment the zygote has formed, demands the unconditional respect that is morally due to the human being in his bodily and spiritual totality. The human being is to be respected and treated as a person from the moment of conception and therefore from that same moment, his rights as a person must be recognized, among which in the first place is the inviolable right of every innocent human being to life."

Also of relevance is Directive 31 of "The Ethical and Religious Directives for Catholic Health Facilities" which states: "Post-mortem examination must not begin until death is morally certain. Vital organs, that is organs necessary to sustain life, may not be removed until death has taken place. The determination of the time of death must be made in accordance with responsible and commonly accepted scientific criteria. In

accordance with current medical practice, to prevent any conflict of interest, the dying patient's doctor or doctors should ordinarily be distinct from the transplant team".

The aforementioned criteria enunciated by the Presidential Commission would probably meet the above mentioned standard of "responsible and commonly accepted scientific criteria" for the determination of death.<sup>40</sup> The consensus among Catholic theologians and medical authorities would appear to be that transplantation of unpaired vital organs is morally acceptable as long as strict adherence to the scientific criteria is observed; that is, the patient is not to be used as an organ donor until he has experienced either 1) irreversible cessation of circulatory and respiratory function or 2) the irreversible cessation of all functions of the brain including the brain stem.

O'Reilly and others have been of the opinion that the criteria based on brain function are unacceptable.<sup>41</sup> They have insisted on confirmation of brain destruction as evidence for establishing that death has occurred. It is implicit in their standard that transplantation of an unpaired vital organ (heart or liver) would never be morally justifiable. Prediction of a fatal outcome would not establish that death has *already* occurred, in their view.

As pointed out by O'Donnell, the standard of care for anencephalics is being violated in many protocols.<sup>42</sup> Life-support measures are constructed so that the newborn will be kept alive while vital organs are being retrieved. The anencephalic is not being permitted to die, but is being kept alive until the removal of vital organs kills the infant. By fabricating the "brain absent" standard, the transplant surgeons would proceed with organ removal as if death had already occurred. One proposed protocol has recommended a gradual cooling process to preserve the organs of the anencephalic, thereby conjuring up a plot analogous to the Jefferson Institute in the novel *Coma*.<sup>44</sup> Others have suggested that issues of life or death are irrelevant, since the anencephalic is "uniquely" subhuman.<sup>45</sup> One transplant surgeon has contended that anencephalics are non-persons and will die anyway and that they are therefore to be preferred as donors to healthy baboons.<sup>46</sup>

The standard of care for anencephalic infants which would be in the child's best interest would be to allow death to proceed naturally with maximum comfort and minimum intervention. This would, in most instances, result in disqualifying the anencephalic as a donor because of organ deterioration. All currently proposed guidelines for qualifying anencephalics as donors would have the effect of doing injustice to these handicapped children by directly causing their death. Establishing medico-legal exceptions to cover the anencephalic will inevitably lead to jeopardy for other neurologically handicapped infants, children, and adults subject to the same lethal measures.

Although all anencephalics have a hopeless prognosis and a brief sojourn in life, they deserve no less protection than other human persons.



As Rabbi Immanuel Jakobovits has pointed out, if one life is construed as having infinite value, then one life is as valuable as many lives.<sup>47</sup> Any small fraction of life has infinite value, because any fraction of infinity is still infinite.

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