The Use of Anencephalic Organs: Historical and Ethical Dimensions

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SHOULD ANENCEPHALIC INFANTS BE USED AS ORGAN donors? The question, as currently stated, is essentially ethical. The need for solid organs from infant donors, we are told, is great and several proposals have been made for harvesting them (Harrison 1986a,b; Walters 1987). Although these proposals have already been subjected to ethical critique (Meilaender 1986; Annas 1987; Capron 1987; Arras and Shinnar 1988; Cranford and Roberts 1988; Fost 1988), certain facets of the proposals and their attendant assumptions have been neglected.

We pay attention to the neglected aspects in this essay, dealing initially with a brief review of the recent history of the struggle toward consensus on a definition of death—a rational prerequisite to other considerations in harvesting organs. Second, we attend to assumptions of the language in which the issue has been couched. Reviewing history and probing assumptions do not, by themselves, yield a definitive answer. Rather they illustrate some of the hazards in the current proposals. Finally, we examine three strategies for using anencephalic organs: redefining death, excluding anencephalics from personhood, and intubating and ventilating them while keeping a vigil for brain death. We argue that each of these strategies fails and that the case for using anencephalic infants as organ donors has not yet been made.

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Contemporary History: Framing the Debate

In 1968 and 1969, reports of heart and kidney transplants using organs from anencephalic infants were published in major American medical journals (Kantrowitz et al. 1968; Martin et al. 1969). Anencephaly is a neural tube defect, which is incurable and uniformly fatal. Infants born with this defect lack brain development above the brainstem. Whereas the bones of the skull are often absent, as are the cerebrum and cerebellum, additional congenital anomalies are usually not present. Approximately 95 percent of those infants born alive die within the first week of life of respiratory failure. In a few rare instances, survival has been documented at weeks (Meinke 1989). Kantrowitz and Martin alluded to these facts when they described their rationale for selecting anencephalic infants as donors and concluded that their worth to very young recipients was clear: They were a "reasonable choice as donors for babies" (Kantrowitz et al. 1969, 789).

Interest in using anencephalics during this time prompted careful study of their organs to determine their suitability for transplant. Thus the article entitled "The Anencephalic Infant as Possible Donor for Cardiac Transplantation," published in 1969, dealt not with ethics, but rather with the post mortem evaluation of the hearts of 79 anencephalic infants to determine weight, abnormalities, and cause of death (Cabasson, Blanc, and Joos, 1969). Another published report was a quantitative, morphological study: "Organ and Body Growth in Anencephaly" (Naeye and Blanc 1971). Past pathology reports were reviewed to establish a baseline for understanding what aspects of anencephaly would prohibit or foster their use as organ donors (Naeye, Milic, and Blanc 1970; Nakano 1973).

These reports reached varied conclusions. What is of interest to us is the overall assumption upon which they were based. A consensus seemed to be that "a minimum of legal, moral or ethical obstacles to procurement of donor material was assured" (Martin et al. 1969, 605). Hence, scientific-medical evidence verifying the organs' acceptability was pursued. This routine medical approach to the use of anencephalic organs provides a stark contrast to the detailed ethical criticism evident in the present debate. It is thus instructive to examine further the medical, social, political, and ethical climate within which it occurred, not in order to establish a precedent for using the organs of anencephalics, but rather to frame a historical context within which current debates can be better evaluated.

Toward Developing an Ethics of Research

World War II is clearly a focal point for this contemporary history. It accelerated belief in, and pressure for, "progress through research." At the same time, the Nazi atrocities, Nuremberg trials, and consequences of the atomic bomb raised new concerns about the ethics of both research conduct and the potential uses of research findings. This double-edged sword did not become apparent in the health policy of the United States, however, until approximately 1968 (Rothman 1987). From 1950 to 1970, the federal government followed its wartime lead and committed vast sums of money for medical research. Its goal was to enlist the aid of science and medicine in curing the health problems of society. The dominant medical ethic of these years was "utilitarian" and, according to Rothman, was profoundly influenced by the practices in human experimentation established during the war years (Rothman 1987).

Citing the establishment of the Committee on Medical Research (CMR) in 1941, which over the war years spent approximately $25 million in research contracts aimed at creating antidotes to dysentery, influenza, and venereal disease, Rothman described the types of human experimentation engaged in at hospitals and universities.

> For the first time, clinical investigations became well-coordinated, extensive, and centrally funded team efforts; experiments were now frequently designed to benefit not the research subjects but others—namely soldiers vulnerable to the disease in question (1987, 1196).

"The CMR," wrote Rothman, "gave the National Institutes of Health not only its organization framework, but also its ethos." It was this "ethos" that Henry Beecher identified in his 1966 article in the *New England Journal of Medicine*, which described 22 instances of unethical research. The injection of live cancer cells into "unconsenting" subjects, for example, was done in the spirit of "winning the war against disease." Beecher concluded that this type of practice was widespread and also felt it was spurred on by the professional rewards for advancement in scientific-academic medicine (Beecher 1966). Rothman's recent examination of Beecher's cases confirmed this and concluded that the "utilitarian ethic" ended in "the public revolt . . . of the late 1960s" (Rothman 1987; Wertz 1973; Starr 1982).

The Uncertainty of "Death"

By the late 1960s, then, the wisdom of health policy in the United States began to be questioned. It was apparent that the advances applauded earlier were creating a host of ethical dilemmas for society. As early as 1957, the International Congress of Anesthesiologists had petitioned Pope Pius XII for guidance regarding their obligations to treat patients who had been "saved" by new techniques in cardiopulmonary resuscitation. These patients had irreparable damage to their brains, yet their heart and lungs could be maintained artificially. The anesthesiologists' petition foreshadowed the later "concept development, research, application and controversy in the use of the construct of brain death" (Korein 1978). In 1958, however, the Papal allocution, "The Prolongation of Life," was straightforward. The Pope decreed that the clarification of death was not the province of the church but the responsibility of the physician. He also asserted that even if the patients described were considered to be alive, no "extraordinary" treatment was required by physicians to maintain them (Pius XII 1958).

This relatively circumscribed concern regarding the definition of death and limitation of treatment by a select group of anesthesiologists burgeoned by 1968. Amid a widespread societal mistrust of all authority and of technology in general, physicians' uncertainties regarding when to declare death took on a new urgency. It was during this tumultuous time that the first successful heart transplant was performed. Dr. Christian Barnard's feat at first seemed to evidence the success of a health policy that invested in medical research. Yet, as Pernick (1988) reminds us, occurring as it did when medical authority was beginning to be questioned, the transplantation triggered the vigorous renewal of a debate that had its origins in antiquity: what are the physical signs of death and how are they to be measured? As in the past, this prompted a revival of philosophical discussion directed at analyzing how medical and legal definitions of death relate to the death of a person. *Newsweek*'s coverage of Barnard's achievement, entitled "When are you really dead?" was indicative of this renewed public and professional questioning (Pernick 1988).

Brain Death: The Emergence of Medical Certainty

The Harvard Ad Hoc Committee's "Definition of Irreversible Coma" (Beecher 1968) challenged physicians to study the natural course of this condition. The study aimed to validate the criteria required to define irreversible coma and use these as new criteria of death. The committee cited the need to change the law, which cited only heart and lung criteria. It also encouraged moral, religious, and ethical inquiry regarding a new definition of death.

The medical community responded to this challenge by producing epidemiological data validating both the irreversible nature of brain death and its unequivocal sequela, "somatic death." The NINDS (National Institute of Neurological Diseases) Collaborative Study, for example, was conducted from 1970 to 1972. It prospectively "followed" 503 comatose patients using four separate sets of criteria to diagnose brain death. All patients died within three months despite all therapy. The Swedish experience and criteria were published in 1972, the Japanese in 1973, and the British in 1977. By 1978, when Peter M. Black published his authoritative two-part article on brain death in the *New England Journal of Medicine*, he could report with confidence that survival after whole-brain damage was not possible, that many different sets of criteria could be used to diagnose this condition, and that widespread brain necrosis could be predicted (Black 1978). Three years later, in July 1981, the President's Commission on Ethical Issues in Biomedicine published its interdisciplinary consensus report on brain death and outlined a model bill to legalize whole-brain death (destruction of the cortex and the brainstem) as a new criterion for death. By 1981, 25 states had adopted some type of legislation to recognize irreversible coma as a new definition of death.

The Persistence of Ethical Ambiguity

This chronology seems to support the widespread impression that brain death was then a reasonably settled area both philosophically and medically. A closer look, however, indicates that it was not. As early as 1976, philosophers concerned with issues in medical ethics proposed what has come to be called a "higher brain" definition of death that equated loss of consciousness (higher cortical activity) with death of a person. This definition encompassed within it patients in a "chronic vegetative state" who have intact brainstems and are able to maintain respiration independently. Veatch (1976), for example, outlined levels of "definition" necessary for a concept such as death and charged that the Harvard Ad Hoc Committee's language confused these levels. He proposed, instead, a three-part framework for formal analysis. One dealt with the concept of death: what is so essentially significant about life that its loss is termed death? A second concerned the locus of death: where in the organism ought one to look to determine whether death has occurred? A third was to identify the "criteria of death": what technical tests must be applied in order to affirm a person as dead?

According to Veatch, the Harvard Ad Hoc Committee report made "serious mistakes . . . in slipping from one level of debate to another and in presuming that expertise on one level necessarily implies expertise on another" (1976, 25). Although the committee stated that it was "simply reporting empirical measures which are criteria for predicting an irreversible coma . . . " (1976, 25), its name pointed more to the question of locus. Furthermore, the first sentence of the report stated: "Our primary purpose is to define irreversible coma as a new criterion for death." This statement presumed a philosophical concept: that a person in irreversible coma should be considered dead. This was neither explicitly stated in the report as presumption nor was it argued. Veatch contended, moreover, that if a redefinition of death were to be made, the Harvard Committee did not go far enough. He then proposed that a "higher brain" definition be included in legislation also (Veatch 1976).

Green and Wikler (1980) criticized Veatch's analysis for confounding "moral and ontological" issues. They specified the "moral, ontological, scientific and policy" aspects of defining death and argued cogently to define brain death as "death of a person" based on a "higher brain" ontological justification. They appealed to "conceptual intuitions," and based their argument on "personal identity" concepts. Wikler, who was staff philosopher to the President's Commission, articulated this alternative definition in an appendix to the commission's report (President's Commission 1981). Youngner and Bartlett later amplified this argument, insisting that "cognitive functions alone enable us to distinguish between death of a person and the life of a mindless organism" (1983, 258). Thus, many of the philosophical arguments for equating permanent loss of consciousness with death were ably articulated and argued by 1983. The President's Commission, however, had precluded their consideration as the basis for public policy in 1981.

Confusion at the Clinical Interface

While philosophers presented cogent analytical arguments against the whole-brain definition of death, neurologists and neurosurgeons, faced with applying it in the clinic, also admitted confusion. The philosophical observations, it seemed, were not mere abstractions. Bryan Jennett and his colleagues (1981) reported their experiences with brain death in three British neurosurgical units. Essentially, they admitted that, in spite of legal protection and medical validation of the concept, physicians nonetheless maintained ventilator support on 326 patients clinically diagnosed as brain dead, "until their hearts stopped" (1981, 535). Peter M. Black (1983) also noted "clinical confusion" over brain death. He reasoned that the brain-death concept was problematic philosophically, for it bypassed discussions of passive euthanasia by defining patients once classified as living as dead (1983, 122). Recall the Papal Allocution of 1958. The brain-death concept was a result of policy makers following the Pope's first alternative, while ignoring the second.

One year later, Black and Zervas (1984) documented continued variation among both neurosurgeons and neurologists in declaring brain death. They concluded that, while it was a *logical* extension of previous definitions of death, as a concept it was both "radical and novel." The neurosurgeon who applied it in the clinic "stands at the interface between changing social norms and individual patient care" (1984, 174). The current proposed legislation on brain death in New Jersey, which poses exemptions for personal religious conviction, and Youngner's recent article documenting the medical profession's "confusion over brain death" suggest that the concept is still being questioned (New Jersey Commission 1990; Youngner et al. 1989).

In spite of this long-standing conceptual confusion about brain death, however, there is a consensus among those who joined to enact brain-death legislation and even among those who opposed it with a higher brain definition (Veith 1977; Wikler 1989; Youngner and Bartlett 1983) that it remain in place as an alternative to heart–lung criteria for diagnosing death. Although philosophical underpinnings are diverse, in sum, there is a pragmatic recognition that the medical criteria for diagnosing whole-brain death are specific, valid, and reliable. One could surely argue that to tinker once more with changing the definition of a concept so fundamental as death, as some are suggesting in the current anencephalic debate, would undermine the overall societal good.

When to Harvest Organs?

The attempts to transplant anencephalics' organs in 1968 and 1969, then, were carried out in the early phase of this redefinition process: a time "when the *legal* definition of death was in a turmoil" (Pernick 1988). Neither medical criteria nor philosophical justifications were clarified. This turmoil, however, did not halt medical investigation into organ transplantation. Those who sought to pursue transplant efforts worked out their own solutions. Some were perplexed whereas others, like Cabasson, found no apparent conflicts:

> Obtaining a donor heart presents a formidable obstacle to all cardiac transplantation in man. The heart is unpaired and vital, and has come to symbolize life itself. It may only be removed and resuscitated after spontaneous clinical death. Thus, for purposes of transplantation, the donor must die of other than cardiac causes within a reasonably predictable period . . . the anencephalic infant who died shortly after birth of noncardiac causes may be looked upon as a potential donor (Cabasson, Blanc, and Joos 1969, 86).

Given this justification, surgical procedures for harvesting organs were outlined to insure that "spontaneous death occurred under predictable conditions" (Cabasson, Blanc, and Joos 1969; Martin et al. 1969).

Anencephalic infants were recognized, in short, as possible "organ donors" and evaluated in terms of their *medical* appropriateness from 1968 to 1971. Neither philosophical nor legal concerns were developed sufficiently to question the practice. This uncharted ground was short lived, however, and ended with a recognition of the medical limitations of transplantation technology generally: an insufficient understanding of ways to combat rejection of the organ by the body's immune system. A mere 20 years later, in spite of advances in immunosuppression, the discussion of the use of anencephalic infants as "organ donors" has reappeared in a context in which ethical debate is clearly both public and interdisciplinary—not solely within the confines of the medical profession. The timid ethical and legal questioning of medical authority, which began in 1968, is now a fact of life. The legal inconsistencies regarding the definition of death apparent in 1968 have been resolved in such a way that anencephalics do not qualify as solid organ donors. Only their corneas, heart valves, and eyes are fit for transplantation; hence, the current debates continue (Capron 1987).

Underlying Assumptions: What We Call It Signals How We Understand It

The Meaning of Donation

One of the most striking features of current discussions regarding "anencephalic donors" is the persistence of the fallacious implication that infants, moreover infants with anencephaly, can *donate* something (Caplan 1983). The logic of donation—an act of giving, or the making of a gift—includes donation by extension: one person giving for another. Thus, parents are the true donors of infants' organs. Yet care should be taken not to claim too much for such extended "donations." Anencephalic infants cannot will their organs, and have no interest in such acts by their parents. The honorific language of "anencephalic donors" is within accepted usage, but it is metaphorical. In the straightforward sense there are no more anencephalic donors than there are baboon donors. The infants themselves are better termed "sources" or "banks." Parents do the giving, and it is a donation not in the full sense, but in the sense that the organs are not for sale and that parents are frequently motivated by altruism.

The Role of Parents

A more troublesome set of assumptions revolves around the typical portrait of the parents of anencephalic infants as desperately seeking to salvage some meaning from their tragedy. The protocol used at the Loma Linda Medical Center, for example, is careful to designate the parents as the "major stimulus" for consideration of their children as potential donors. "These parents want something good to come from their tragedy; they want their child's life to have 'meaning' and the normal and healthy organs of their child to live on" (Ashwal et al. 1988). This is understandable, but it does not constitute a justification.

First, it looks as if parents have here become patients. Transplanting their infants' organs becomes a form of therapy for them, a way of providing some meaning. The assumption of a therapeutic meaning for parents—while having some clinical precedent—is not the main question and to emphasize it only confuses the issue. Care must be taken to avoid putting the parental grief process in the center of the picture, for it all too easily displaces the infant from the focus of attention. When parental grief is seen as a medical problem, there will be great temptation to treat it. The all-but-expressed assumption is that transplanting the anencephalic's organs would not only be therapeutic for the parents, but it would be also the best therapy possible, perhaps the only "meaning" possible. This is surely not the case, for parents find many ways of resolving their loss and locating a meaning for the tragedy of bearing children with anencephaly.

What is most frequently admired about these parents is their manifest altruism. Altruistic acts are usually more admirable than egoistic or self-interested ones. Let us assume here (for the sake of argument) that the parents' motives are entirely altruistic. Even so, objections are possible. Not all altruistic behavior is good. Altruism describes only what motivates an action, not its style, form, content, or outcomes. Actions can be well motivated and selfless, but still self-deceptive, ill-advised, reactive, foolhardy, inappropriate, or destructive. In short it is no contradiction to say of actions that they are motivated by altruism, but on the whole morally unjustified.

Moreover, one may question whether a consent based on altruism is informed in the sense of understanding outcomes and alternatives. That is, the altruistic gesture may mask well-known psychological issues inherent in decisions made near the end of life. Jackson and Youngner pointed this out in the context of an intensive care unit (ICU) setting in which a "superficial preoccupation" with important issues such as "patient autonomy" and "the right to die" threatened to lead physicians to make clinically inappropriate decisions (Jackson and Youngner 1979). Patient ambivalence, depression, hidden problems, fear, erroneous perceptions, and misconceptions by staff were cited as typical issues underlying a competent patient's express wish to die. In five of the cases, after careful attention by staff to the underlying problems, the wish was reversed. In one patient, ambivalence was never resolved. Jackson and Youngner concluded that when physicians deal with complex psychosocial issues facing critically ill patients, an important aspect of their professional responsibility is to probe a patient's or family's statement to explore further or clarify it. Not to do this, they contend, is a moral breach. A similar breach of professional responsibility could also be triggered by superficial acceptance of altruism from distraught parents. A decision of altruistic parents to donate organs of their anencephalic infant may be, of course, an informed and appropriate one. Yet neither parental "altruism" nor parental "therapy" are determinative factors. The central, unresolved issue remains the status and significance of the anencephalic infant himself.

Harming and Wronging

A third cluster of assumptions involves the portrait of anencephalic infants as "beyond suffering" and having "no interest in treatment." These phrases are usually correlated with other descriptions: "completely unconscious," "truly dying," or "utterly hopeless prognosis" (Cranford and Roberts 1988). For example, many who have written about anencephalic infants have discussed the inappropriateness of using procedures described in the President's Commission Report, which focuses on the "best interests" of infants (President's Commission 1983). Anencephalics, it is sometimes said, have no interest at all. Therefore the question shifts to other interests: the parents' interests, the potential recipients' interests, society's interests, and so on. There is a general interest in seeing that infants with anencephaly are treated humanely, so there are brief homilies in most writing about how everyone suffers in the absence of respectful care. Although we cannot cause suffering in anencephalic infants, we can cause suffering in ourselves and others if we do not treat them with due respect.

This is a salutary view, but insufficient. It assumes that infants with anencephaly cannot be harmed in the sense that pain does not register anywhere. This may not be true. The diagnosis of anencephaly covers a range of infants (Baird and Sadovnick 1984). Although the cerebral hemispheres and forebrain (telencephalon) are absent, the major subcortical nuclei including the thalamus (diencephalon) are usually preserved. Individuals who have had their entire somatosensory cortex damaged by a stroke or injury or removed surgically can appreciate acute and chronic pain at the thalamic level. Thus, it is impossible to be certain which anencephalic infants feel pain (Moore 1974; Kandel and Schwartz 1983). Hence, we must be careful about categorical assertions that anencephalic infants are "beyond suffering."

Yet even if we grant, for the sake of argument, that anencephalic infants cannot experience pain, and therefore cannot be harmed, such infants could still be *wronged.* If we lie to our friends, we may not harm them, but we wrong them, even if the lie is completely undetected. Likewise the dead can be wronged, even though they are beyond harm to an even greater degree than anencephalic infants. For example, the dead can be profoundly wronged by being left unburied. It is precisely this sort of wrong that forms the moral tension of Sophocles' *Antigone* (Sophocles 1954). Or one can be wronged by having one's history or honor maligned. Think here of Achilles dragging the body of Hector around the walls of Troy from the back of his chariot in full view of the city (Homer 1951). Hector was not harmed, but he was wronged. Priam (Hector's father) and Troy were both harmed and wronged. Infants with anencephaly, even if beyond harm, are not beyond being wronged. If the dead can be wronged, all the more so can the living. Protocols that prolong the dying of anencephalic infants to harvest their organs may not harm them, but they do wrong them. Prolonging the dying of anencephalics in ways and for purposes that cannot conceivably benefit them diminishes their value. It is a mark of disrespect, for it simply uses them as the track on which the train of our purposes can run.

This discussion probes the assumptions underlying the debate to harvest anencephalics' organs. It is intended to examine and refine the moral language we employ to discuss the issues, not to settle the matter. We will consider three specific strategies that have been suggested for procuring organs from anencephalic infants. Our assumption still is that the goal is worthy, in terms of outcomes. The question is whether a morally licit path to achieve it can be found.

Strategies: Are Any of Them Morally Licit?

Redefining Death (Again)

One strategy is to redefine "death" so as to include anencephalics (Capron 1987; Walters 1987). And here we do mean "redefine." The concept of whole-brain death is not a redefinition, but a refinement and updating of measurements for determining whether persons are dead, and when they are dead, in the presence of life supports or other interventions or conditions that obscure ordinary means of determining death. To include anencephalics among the dead is to redefine death. This strategy centers upon the debate, cited earlier, that resurfaced in 1968 when the brain-death concept was first being discussed for policy purposes. Then, as now, there were supporters for a "higher brain" concept of death, one that conceptually distinguished "death of a person and the death of body parts." Prior to current arguments, however, those who sought to redefine death on the basis of higher-brain criteria did so on conceptual grounds in response to a widespread societal debate on how to define death. They were prompted, not by a need to secure organs from anencephalic infants, but rather by philosophical intuitions and beliefs. Green and Wikler (1980), in fact, specifically urged that the "moral practices" surrounding the dead (such as transplantation) not motivate new definitions. Harrison, in contrast, has suggested the category of "brain absent" for anencephalics, which he believed would be equivalent to declaring them dead (Harrison 1986a,b). Truog and Fletcher (1989) have argued that anencephalics fit the "spirit" of the whole-brain death standard as expressed in the President's Commission Report.

The problem, of course, is that such a redefinition, or return to the "spirit" of the old definition, would fly in the face of the evidence. Infants with anencephaly are breathing *without* technological assistance, their blood is circulating, and they move and react. Calling them dead has an Alice-in-Wonderland quality. It is legally convenient and can be philosophically defended, but it is in our view empirically false. (We will consider the appellation "never alive as persons" as a synonym for death in the next section.)

In another context, both Youngner and Mahowald have argued for using emotional reactions to psychologically difficult acts that occur in transplantation procedures to serve as markers (Youngner et al. 1985; Mahowald, Silver, and Ratcheson 1987). These markers in turn are used to alert policy makers to the need for creating wedges. We consider current brain-death policy as such a wedge, strategically placed so that anencephalics and others in varying compromised states (who are alive, and some of whom should be kept alive) are not swept in under a redefinition. Careful scrutiny of both the professional and lay communities, in sum, suggests that confusion still surrounds the current brain-death definition (Black 1983; Pinkus 1984, 1985; Youngner et al. 1989); and we recognize, with Pernick, that:

> In the past as now, difficulties in defining and diagnosing death often did spring from new medical discoveries, especially in such areas as experimental physiology, resuscitation, and suspended animation. . . . The resulting debates, past and present, were the product of a complex interplay of social, professional, and ethical changes, and cannot be understood as simply the result of new medical knowledge. Death has never been completely definable in objective technical terms. It has always been at least in part a subjective and value-based construct (Pernick 1988, 17).

Yet, to say that the definition of death is in fact partially subjective and value based is not to say it is arbitrary. A wedge signals something important, even if logically imprecise, and the objections to strategies aimed at removing it are compelling.

In sum, the current whole-brain-death criteria are widely accepted legally, and are medically precise and reliable, even if philosophically troubling to some. To press for a higher-brain redefinition of death in order to satisfy intuitions, or to harvest organs, is only likely to lead to clinical confusion and public mistrust.

The Question of Personhood—and the Question of Death

A second strategy is to exclude infants with anencephaly from the realm of personhood. If anencephalic infants are not "persons," but belong to some lesser category of beings, then the moral opprobrium and legal restraints from harming, wronging, killing, or using for other purposes are diminished. Tristram Engelhardt and Joseph Fletcher, to cite authorities from very different traditions, would agree that such infants are nonpersons: for Engelhardt because they lack rationality (Engelhardt 1986), for Fletcher because they would fail all 21 of his "Indicators of Humanhood" (Fletcher 1972). Under this view infants with anencephaly would be considered human beings, in the species sense (they are not horses, or elephants, or baboons), but they would not be considered persons in the legal and moral sense, which means they would not be protected by rights or a stringent set of obligations.

There is currently no legal interpretation in the United States that would support using the organs of anencephalics based on the view that they are either dead or are not persons.

A sweeping and stigmatizing effort to exclude such infants is exemplified by Martin and his colleagues, who, in a 1969 report in *Surgery*, simply designated an anencephalic donor as a "monster" (Martin et al. 1969). The term "monster" may be technically a correct designation for anencephalics with respect to teratology, the study of malformations (from the Greek *terat*, meaning marvel, portent, or monster), but the use of this term threatens to beg the moral issue. Such designations not only exclude personhood, they exclude benign characteristics as well. The interpretation implied by the terminology in this 1969 report is of two beneficent acts: first, ridding us of the monster, and secondly, using monster parts for a human good.

More recent "personhood" arguments favoring use of anencephalic organs are more sophisticated. A recent issue of the *Journal of Medicine and Philosophy* was devoted, with one exception, to such arguments. Two of the essays, one by Cefalo and Engelhardt (1989) and the other by Zaner (1989), are especially noteworthy. Cefalo and Engelhardt distinguish between "human biological life" and "human personal life" (Cefalo and Engelhardt 1989). They contend that anencephalics possess the former, but not the latter. Persons, in their view, must have "the minimum biological substrata, which is the basis for sentience." Sentience is "the necessary condition for being alive as a person." In the absence of sentience it is appropriate "to declare a person dead, or to declare that a person never developed" (1989, 39). They would accordingly welcome the extension of this concept to persons in persistent vegetative states as well as anencephalic infants.

Zaner pursues a line of thinking that also hinges on a redefined notion of personhood. Persons have higher-brain function, or what Zaner calls "the neurological wherewithal" to support moral and social agency. He concludes that anencephalic infants are "never 'alive' in the only significant sense for morality and social policy—as persons" (1989, 72).

The nuance in argument here is the combining of a concept of death with a concept of personhood into an explicit normative threshold. This characterizes the essays of both Cefalo and Engelhardt and Zaner, and it creates a new standard, "alive as a person," which relies on contested interpretations of both the key concepts. This tandem concept is a natural extension of previous thinking on personhood that shares the assumptions of these authors. The innovative aspect of this tandem formulation is how it functions to up the ante. "Alive as a person" asserts not one criteria for admission to legal and ethical protections, but two. By combining these concepts into a single, high-threshold formula, it is possible to shift the emphasis between concepts, accommodating one aspect of an opponent's claims while denying the other. Insofar as anencephalic infants are considered alive, they are merely alive biologically and not as "persons." Insofar as anencephalic infants are considered as persons, they are nonexistent, not "alive" in the sense of capable of present or future agency.

What is noteworthy here is that both "alive" and "person" have specialized senses and one term is used to specify the relevant aspect of the other. We contend that definitions and criteria for determination of death are one item, definitions of personhood quite another. They should be taken separately and not placed in a specialized, interlocking relationship of redefinitional circularity. Redefinitions of death were addressed earlier. We now turn to the problems of defining personhood.

In large measure the impetus for redefinition does not spring from any merit intrinsic to the question, nor from our concern *for* the group in question, but rather because we have some use in mind for them. Otherwise, the issue of "personhood" would be of only academic interest.

"Person," moreover, is not an empirical concept, as the abortion debate has illustrated vividly. Who is and is not a person has no definitive empirical answer. It cannot be settled physiologically by listing parts, or by simple reference to sentience, or to a biological substrata. It is, of course, true that there are biological prerequisites both for life and for being recognized as a member of the human species. Anencephalic infants satisfy both of these. To affirm these while denying the higher-level designation of personhood is simply to express a particular moral and political persuasion, not to offer evidence. "Alive as a person" offers no new basis for distinguishing persons from nonpersons, only a recasting of the old assertions into a more sophisticated and slippery conceptual nexus.

"Person" is fundamentally a social and moral term. Inclusion of someone in the realm of personhood tells us little about him empirically or aesthetically, but it does forcefully designate how he is to be treated. It also says a great deal about ourselves as definers and designators of personhood. This has been powerfully expressed by Stanley Hauerwas in an article entitled: "Must a Patient Be a Person to Be a Patient? Or, My Uncle Charlie Is Not Much of a Person but He Is Still My Uncle Charlie" (Hauerwas 1977).

Efforts to redefine personhood, especially for reasons of exclusion, are self-reflexive: they say more about our basic humanity than about those we seek to redefine. These redefinitions dispute the boundaries of the community to which we believe we belong: how inclusive or exclusive it is, how open to the weak and seriously handicapped. "Person" should not be used as a regulative concept, that is, one providing a basis for policy. It is essentially a moral marker in our sensibilities for designating political and social standards. Its use as a criterion with precise biological marks always runs the risk of being preemptive and stopping conversation. Like preemptive bids in contract bridge, designations of personhood or nonpersonhood tend to capture and close off the negotiations. One aim of ethics is to keep the conversations about key moral concepts open, so as to make our actions and policies as well informed as possible. Definitions of personhood militate against that.

Cefalo and Engelhardt (1989) and Zaner (1989) offer thoughtful arguments for a redefinition of personhood. Their arguments have an intuitive appeal, especially if one relies on personal identity concepts, as Green and Wikler (1980) have done. Still, we believe their reasoning is not persuasive. This lack of persuasiveness, it is important to note, should not be taken to imply that there is irrefutable evidence for the personhood of anencephalic infants. Our point is rather that personhood does not lend itself to definition or redefinition in this way at all. No definitive "proof" can be forthcoming regarding the personhood of anencephalic infants because (as with all definitions of "person") the antecedent values of the definers profoundly shape the definition and determine the criteria relevant to a definition.

The issue of personhood is at best provisional and heuristic, not susceptible to precision or proof. This means we should use this concept cautiously and refrain from making it bear the freight of regulations or policy, especially policies that would exclude some from moral regard and legal protections. Thus, we strongly disagree with Cutter's summary assertion in the *Journal of Medicine and Philosophy* that the "general rational arguments" offered settle the question of whether or not the use of anencephalic organs is a serious moral wrong (Cutter 1989, 94). The burden of argument still lies with those who would exclude anencephalic infants from the human community through redefinition. In the absence of compelling arguments, retention of the moral and legal standing designated by personhood for anencephalic infants is both prudent and humane.

Here it may be useful to note similarities and differences between definitions of death and definitions of personhood. Both are value laden in the sense of not being completely definable in objective technical terms. They differ crucially, however, in that the occurrence of death is an event to be discovered, rather than a convention to be arbitrated in terms of social needs. Definitions of death that do not seek to reflect that fundamental biological referent would be useless. We use criteria to assess if and when death has occurred (not when we want it to occur), and these criteria need periodic review to compensate for the ways technologies can mask the signs of death. Death is, to be sure, a personal, social, and cultural event, but it accrues these meanings because it is first and foremost a biological reality, captured in better or worse ways by definitions and criteria. Personhood, by contrast, involves biological thresholds, but takes its main weight as a concept from its moral and political force. Personhood is a convention, if (to be sure) a convention of enormous importance in the modern world.

Not all would agree with our views here and perhaps many of those we criticize are of a different persuasion. Part of our objection to the notion "alive as a person" is precisely that it treats "death" and "person" both as conventions to be arbitrated rather than acknowledging the differing logic between these concepts.

Temporizing

The third strategy is one of temporizing. The great technical problem with the use of anencephalic organs is their deterioration during the dying process. The Anencephalic Organ Donation Committee of Loma Linda Medical Center, and perhaps other groups, have devised strategies to keep the organs fresh by intubating and ventilating the infants for a period not to exceed seven days, while regularly checking for brain death (Ashwal et al. 1988). The seven-day limit was established in part as a gesture of respect for the doomed infants and to forestall criticism that they are being kept alive merely as organ banks. We call this policy "seven-day utilitarianism." The reasoning seems to be that one can use anencephalics as means for others (rather than what Kant [1959] would call an "end in themselves") for a week, but that the utility runs out after that. Consistency would argue that if it is good to prolong the dying of such infants for a week, it would be good to do so for two weeks, and so on. If there is concern about the process of interfering untherapeutically in the dying of anencephalics, why does this concern only become compelling after seven days? Why is it not compelling on day one? We are not arguing here for perfect consistency, but radical fluctuations such as this seem to be in search of a moral rationale, rather than well grounded in one.

Ordinarily, we work diligently to be certain that patients are not overtreated when treatment is futile. Limitation of treatment when it would be useless is now generally recognized as an appropriate part of good patient care. The temporizing strategy proposed is overtreatment of anencephalic infants—infants who are dying and who would never be subjected to such technologies of death prolongation were we focused only on what would be proper care for them. The proper care of these infants should be the focus.

Conclusion

In this essay, we have reviewed contemporary history, probed assumptions, and questioned strategies. Our approach, of course, has its own assumptions. It relies on conventional moral notions about respect for the rights of persons and protection of the vulnerable. One can conceive of a society in which these notions did not have a central place. Such a society might place greater value on meeting the needs of potential organ recipients than on protecting donors. To be sure, such a society would use different terms to describe and analyze the issues discussed here. It should be noted, however, that those who favor the use of anencephalic organs do not argue for a change in the moral terms. Rather, they seek to redefine the actions they propose to bring them into accord with these terms. The point of our criticism is that none of these redefinitions is persuasive.

In the future there will likely be calls to alter statutes and recategorize anencephalic infants as "dead," "nonpersons," or in some other way remove them from moral and legal protections and deny them a locus in the human world. Such efforts should be resisted.

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