Transplantation Tragedies

BY THOMAS A. SHANNON, PhD

The recent reporting of the tragic circumstances of Theresa Ann Campo Pearson's medical condition and death focuses our attention yet again on the complexities that surround birth and death, particularly when some see a possibility for bringing good from a tragedy.

Theresa Ann suffered from the fatal neural tube defect anencephaly. Although she survived for a few days after birth, the absence of a major part of her brain clearly meant she would die shortly. Her parents requested that her organs be donated for transplantation immediately, but the hospital refused—and a Florida court forbade harvesting her organs before her heart and breathing stopped, even though the organs would not be suitable for transplant at that time.

Two things were clear about her situation: The defect was fatal, and she did not meet the current definition of death, which is the absence of all functions of the brain, including the brain stem. The presence of her brain stem, which was physically intact enough for her to breathe on her own and to maintain her heartbeat, allowed her to live a short time.

Theresa Ann's plight has prompted two major lines of debate about cases involving a person's lack of neocortical activity. The first debate is on the definition of death, and the second concerns the moral status of infants with anencephaly.

A Definitional Shift

The current criteria used to declare death, first developed in 1968, center on the absence of activity in the entire brain. In the original article proposing these criteria, the motivating factors were to free up bed space in intensive care units and to obtain physically intact organs for transplantation ("A Definition of Irreversible Coma as a Criterion for Death," *JAMA*, August 5, 1968, pp. 337-340). These arguments for changing the definition of death are essentially utilitarian or consequentialist in nature, as opposed to other philosophical examinations of the issue. This approach was also explicitly incorporated in the 1979 Kansas legislation on death, the first state statute to include brain criteria in a definition of death.

Dr. Shannon is Paris Fletcher Distinguished Professor of the Humanities, Department of Humanities, Worcester Polytechnic Institute, Worcester, MA.

Two shifts from the current standard of whole-brain criteria for declaring death are proposed in the debate about the use of organs from infants with anencephaly. One proposal is that only neocortical criteria be used to define death: That is, if the neocortex is irreversibly damaged, death will be declared even though the brain stem remains functioning. Another is that infants without intact brains be excluded from the current definition and considered dead by virtue of brain absence.

The basis for these proposed shifts is that the neocortex is the physical presupposition for those activities which seem to make us unique beings: abstract thought, self-consciousness, and the capacity for relationships. As John Fletcher of the University of Virginia's Center for Biomedical Ethics recently said in an interview in the *New York Times*, "What makes us human is what goes on upstairs in the brain, not downstairs in the brain" (Sabra Chartrunc, "Baby Missing Part of Brain Challenges Definition of Death," March 29, 1992, p. A19). Thus, the argument goes, the absence of neocortical activity or of the neocortex itself would be an appropriate neural criterion by which to define death.

This definitional shift gives primary relevance to the physical basis for certain kinds of activities and characteristics. Although we certainly value self-consciousness, abstract thought, and the capacity for personal relations, it is unclear why these capacities and the physical characteristics that make them possible should be so privileged. Such a shift in definition assumes a normative link between biology and pershonhood and comes close to claiming that humans derive personal status, if not personhood itself, exclusively from neural structures or activities.

The redefinition also seems to suggest that the self is somehow contained within the brain, which would be a scientific model of Descartes's

philosophical understanding of the mind-body relation. This is a problematic understanding of the person as an incarnated being. That is, the soul, for Descartes, was located in the brain (at the pineal gland) and was responsible only for spiritual and intellectual aspects of human activity. The body was a machine that was radically distinct from the soul and operated independently.

Finally, this definition carries the risk of an assumption that if the being did not reach the legislatively defined threshold, that being would be considered valueless, as if a certain physiological configuration conferred value and status on the individual.

I believe that either a change in the current definition of death or an exemption to it is a bad idea. The current definition of death of the whole brain protects human dignity and the human person by not singling out one dimension of the person—self-consciousness—and by avoiding too close a relationship between personhood and specific parts of the brain. Why, for example, is it only what goes on in the brain—whether upstairs or downstairs—that makes us human? It is clear that the brain integrates all other physiological activities, but it is not clear that the brain represents the essence of humanness.

Moral Status

In addition to these definitional problems, a second major issue has to do with the moral status of infants with anencephaly.

Personhood as a Moral Basis One dimension of the moral status argument looks to personhood—regardless of how it is defined—as the critical moral basis for prohibiting infants with anencephaly from being organ donors. Such an argument is, in my judgment, an extension of the philosophical position that personhood begins at fertilization—that is, for all practical purposes, the union of egg and sperm constitutes the presence of a genetically unique individual who is a human person with full moral and legal status.

This line of argumentation has two problems. First, regardless of one's definition of personhood, definitions are impossible to validate in beings who can provide no evidence of meeting the definition. Thus, unless one wants to assert the personhood of a particular being simply by stipulation or on the basis of certain physical characteristics, attempting to ground the protection of infants with anencephaly on personhood seems problematic. Either one has a definition that cannot be tested, or one privileges a particular physical structure. The former position is arbitrary at best and capricious at worst. The latter position derives a moral "ought" from a biological "is," which is the naturalistic fallacy, making a particular biological or social arrangement normative or absolute even though such a configuration is either contingent or in a process of development. Although an intact central nervous system is a necessary part of the definition of a person, it alone is not sufficient. An intact nervous system gives the biological presuppositions for acts of the person, as opposed to acts of human nature, but personhood—however defined—is not identical with physical characteristics.

Why should personhood be the only or even the primary basis for securing moral status and worth?

I argue that the philosophical category of personhood, regardless of how it is defined, does not apply to Theresa Ann, nor to any number of other members of the human species. But why should personhood be the only or even the primary basis for securing moral status and protection? Why should the fact that such infants do not and will not have sentient or self-conscious life mean that they can be treated with less respect?

The fact that the brain of Theresa Ann consisted of only a brain stem neither ends the moral analysis of the situation nor provides the only moral framework. To paraphrase the title of an article by Stanley Hauerwas, Theresa Ann may not be much of a person, but she is still Theresa Ann (*Truthfulness and Tragedy*, University of Notre Dame Press, Notre Dame, IN, 1977, p. 127). She is a living, individual member of the human species. She was born into a family and exists in a web of family, social, and legal relations.

Does she lack physical structures critical for her development, both physically and psychologically? Yes. Does she suffer from a fatal neural defect? Tragically and sorrowfully, yes. Do these factors have normative moral relevance in defining or categorizing her moral worth? Yes, but not completely. Once we put such normative value on

physical characteristics or psychological capacities, then we have taken yet another step down a familiar path, the path of social discrimination. Her moral status does not mandate that we do all we can to maintain her life, but it should be recognized and considered in decisions made on her behalf.

The fact that it would be difficult, if not impossible, to argue that she is a person does not leave us without any basis for conducting a moral analysis. She is still Theresa Ann and, as a living member of the human species, still embodies values that make some claims on us. Her very being constitutes a grounding for her moral status and the social protection appropriate to that status. Her very existence manifests a primary value and sufficient ground to prohibit her being used as an organ donor before her death.

Instrumental Value Another dimension of the moral status argument assigns only instrumental value to an infant with anencephaly—that is, sees such an infant as valuable because his or her donated organs will allow others to live and will allow the parents to draw some consolation from a bitterly tragic situation. Such a position can bypass the infant's intrinsic value and put him or her in the position of being only a means to others' ends. Thus highlighting the role of such infants as the source of organs can cause us to neglect the moral claims, minimal though they may be, they make on us.

The Slippery Slope

Finally, there are many questions about organ donation itself. From its beginning questions have arisen about the conflict of interest between patients' well-being and the desirability of their being organ donors. The potential of exploitation through an underground market in organs is another issue often raised. Will patients who are in a persistent vegetative state become another exemption to the definition of death? What about those with severe retardation, those who are terminally ill, and (now that capital punishment is in vogue) those about to be executed?

This is clearly a slippery slope or wedge argument, which says that if you make one exception or take one step down such a slope, then you will not be able to stop. Such an argument is difficult to validate in advance. And there is a tremendous shortage of transplantable organs, pressure on healthcare providers to obtain them, real people who would benefit, and a cultural mandate to save as many lives as possible irrespective of cost—either morally or economically. Such a climate is conducive to reducing infants with anencephaly to a means for a variety of ends, much to their detriment.

We cannot adequately resolve this question on a case-by-case basis, as if such cases had no relation to each other and no social impact.

The Larger Debate

Arguing against parents who are trying to make some sense and find some good in the pain they are experiencing seems cruel and mean spirited. Yet trying to protect the dignity and value and even the physical integrity of infants with anencephaly has a value and good beyond the particular case. Indeed, another dimension of the parents' agony is that they are caught in a larger debate about a critical ethical dilemma that has not been resolved.

However, we cannot adequately resolve this problem on a case-by-case basis, as if such cases had no relation to each other and no social impact. Such a practice of case-by-case resolution is setting a policy by implication. A better approach is to establish a general policy in advance of the development of social practice. This would help clarify the situation and prevent last-minute crises—for although the death of Theresa Ann brings closure to this particular situation, cases similar to hers will arise again.

I recommend a policy that excludes infants with anencephaly and similarly situated individuals—such as persons in persistent vegetative states, those with severely injured brains, or those with severely reduced brain function from organic causes—from being organ donors. Admittedly, such a policy could constitute an additional burden for the parents by overriding their wishes. Nonetheless I think the use of such infants as organ donors compromises their bodily integrity by removing their organs before death, reduces them to a means for others' ends, and is socially discriminatory in that it privileges the health needs of one group by compromising the care of another. □