

Anencephalic neonates as organ donors

Dr Donna Knapp van Bogaert, Part-time senior lecturer, (Biomedical Ethics - Medunsa and Univ. of Pretoria.
Prof Gboyega A Ogunbanjo, Dept. of Family Medicine & Primary Health Care,
 Medical University of Southern Africa (Medunsa), Pretoria

Introduction

The problem of using anencephalic neonates as potential organ donors is a highly charged emotional issue. In this brief article, we are unable to address all of the ethical issues involved but present an admittedly superficial overview for further reflections. (*SA Fam Pract* 2003;45(3):51)

Dr A: Anencephaly is a developmental abnormality in the central nervous system that, according to a Task Team on Anencephaly results in the "congenital absence of a major portion of the brain, skull and scalp."¹ Anencephalics face a certain and usually imminent death. In addition, anencephaly is such an emotional disaster for parents that when faced with the birth of an anencephalic baby they want to find some meaning and comfort. One way to approach this is to donate the neonate's organs with the hope that someone else may benefit. In this thinking, there are so many children in need of organ transplants that some children may be spared death while for others the quality of their lives may be improved by organ transplants.

Dr B: Those are pretty compelling reasons for organ donation, but what are some oppositions to this view?

Dr A: First, there is an ethical and legal prohibition against removal of their life-necessary, non-removable organs before death. This is called the "Dead Donor rule."² This rule ensures that one person's life will not be sacrificed for the benefit of another person, even if the idea behind it is to maintain or even give another person life. The basis for this lies in the Kantian admonition not to use people only as a means to an end.

Dr B: That's right but are anencephalic neonates actually or potentially persons? It seems to me that they are not either. After all, they can't or never will they be able to for example, experience pain, pleasure, think, or communicate.

Dr A: I accept your point but the Dead Donor rule also serves to reassure people who are organ donors that they be in fact, actually dead before their organs are harvested. In other words, it provides for the maintenance of their interests.

Dr B: Are you saying that if the Dead Donor rule is not applied then this might open the way for abuses of exceptions to the rule for example, taking organs from seriously handicapped persons in persistent vegetative states or severe dementia?^{3,4} That sounds like a 'slippery-slope' argument.

Dr A: That is what is implied although personally, since anencephalic neonates have no consciousness as

opposed to the others you have mentioned, then it seems to me that to begin with such arguments is analogously incorrect. What I think is the major issue is the question of whether it is ethically permissible to consider an anencephalic neonate a potential donor while it is still "alive" as opposed to when it has "died".

Dr B: Or whether it is morally acceptable to remove organs from anencephalic neonates only after they have 'naturally' died or before they die as long as there is parental consent and certain other ethical protections?

Dr A: Yes. I think that is a fair representation of the major dilemma. As you know, the criterion of brain death remains controversial and legal issues are involved as well. On the ethical side, one question seems to be when is "death", "death"? Is it when there is cessation of cortical functioning, in other words the absence of cognitive function that in itself implies the absence of personhood? Or could 'death' be conceived as by using the criterion of being "brain-absent"? In this thinking, because anencephalic neonates, lack integrated brain function they are close to being brain-dead and will inevitably die. They do not have the potential to become persons.

Dr B: In addition, there are other considerations such as the actual diagnosis of anencephaly must be made by doctors with special expertise whose interests are viewed as non-conflicting with those of the transplant teams, that the parents of the anencephalic neonate initiate the idea of organ transplant, that compliance with any country's existing laws are upheld, and that all of the above considerations follow the ethical guidelines for organ transplant of one's professional licensing body.⁵

Dr A: Food for thought.

Dr B: That's the idea

References

1. The Medical task Force on Anencephaly. The infant with anencephaly. *New England Journal of Medicine*, 1990; 322: 669-674.
2. Arnold, RM, Younger SJ. The Dead Donor rule: should we stretch it, bend it, or abandon it? *Kennedy Institute of Ethics Journal*, 1993; 2: 263-278.
3. Capron AM. Anencephalic donors: separate the dead from the dying. *Hastings Center Report* 1987; 17 (1): 5-9.
4. Shewmon DA, Capron AM, Peacock WJ. The use of anencephalic infants as organ donors: a critique. *Journal of the American Medical Association*, 1989; 261: 1173-1178.
5. Orentlicher D. Physician-assisted dying: The conflict with fundamental principles of American law. in, *Medicine Unbound: The Human Body and the Limits of Medical Intervention*. R.H. Blank and A.L. Bonneck-sen (Eds.). New York: Columbia University Press. 1994: 257-268.