
Anencephalic Newborns as Organ Donors

Legal and Ethical Issues

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I believe that each human life is of infinite value, and since infinity cannot be multiplied or divided, remaining implicit in its infinity, so too is all human life precious and worthy of protection, no matter how long or short it may be.

Alison Davis

Introduction

Organ transplants have developed over the last few decades to provide hope for patients suffering from chronic or fatal illnesses. The reality of this hope obviously depends on the availability of organs. In most cases these come from cadavers satisfying the dual criteria of death and having suitable intact organs.

Cadaver organs for transplantation in older patients come primarily from the victims of accidents, especially automobile and motorcycle collisions.¹ Relatively few newborns and very young children die under these or other circumstances that would make them suitable organ donors. In the case of infants, it is rare for death to occur as a result of a brain insult which leaves their organs intact and suitable for transplantation. Hence for infants requiring an organ transplant, there is a shortage of organs and a painstaking wait for suitable donors².

Various sources of infant organs for transplantation have been proposed. These include other animal species, human foetuses and dying infants. One group of newborn infants — anencephalics — have received attention as a source of organs for transplantation.

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1 AL Capron 'Anencephalic Donors: Separate the Dead From the Dying' *Hastings Center Report* 1987 17:5-9.

2 Medical Task Force 'The Infant With Anencephaly' *The New England Journal of Medicine* 1989 321:344-350.

The practice of using the dying anencephalic infants for organ transplantation purposes appears on the surface to offer many benefits. For example

- instead of two babies dying one is saved;
- parents of donors can derive satisfaction from knowing some good has come from their personal tragedy;
- society is spared the cost of caring for a terminally ill infant.

Despite the apparent benefits, the issue of anencephalic organ donation has been the centre of considerable controversy.

The questions raised are not primarily medical in nature, but rather they revolve around fundamental ethical, legal, political and philosophical debates about the definition of death, the justification of non-therapeutic intervention, candidacy for organ transplantation, and putting society on what has been called the 'slippery slope'.

In this review, some of the medical, legal and ethical issues of using anencephalic infants as organ donors will be outlined and evaluated.

Medical Aspects of Anencephaly

Anencephaly is defined as the congenital absence of the skull, scalp and forebrain³. The amount of actual nervous tissue present varies from a few grams to normal, full-term brain weight. Similarly, the brainstem may vary from being totally absent to relatively normal⁴.

The cause of anencephaly is unknown. The defect originates early in embryogenesis. It can in most cases be readily detected during pregnancy and depending on the choice of the parent(s), the pregnancy is usually terminated by elective abortion. Detection late in pregnancy or at birth however, it not uncommon.

If birth does occur, diagnosis of anencephaly is obvious in the great majority of cases, with there being little chance of mistaking it for other conditions. Even so, the contention that misdiagnosis can never occur is not true⁵. Hence policies developed with the intention of being applicable only to anencephalics, could affect other patients with congenital brain malformations by virtue of misdiagnosis, even though the probabilities of such errors are low.

The natural prevalence rate of anencephaly in the United States in 1988 was about 0.3 per 1000 births, making the number of anencephalics potentially born in

3 JR Botkin 'Anencephalic Infants as Organ Donors' *Pediatrics* 1988 82:250–256.

4 Shinnar & Arras 'Ethical Issues in the Use of Anencephalic Infants as Organ Donors' *Neurologic Clinic* 1989 7:729–743.

5 DA Shewmon 'Anencephaly: Selected Medical Aspects' *Hastings Center Report* 1988 18:11–19.

the United States to be about 1200 per annum⁶. The life span of an anencephalic newborn depends on the severity of the brain stem and the intensity of care provided. Most die within a week of birth⁷.

Only a fraction of anencephalics are potential organ donors. It has been estimated that the total number of infants likely to actually benefit from transplantation with anencephalic organs in the next decade, will be only of the order of 40 per annum in the United States⁸.

Despite these low numbers and the fact that harvesting anencephalic organs may be not a rich source as had been predicted, the controversy continues. The number of infants needing heart, liver and kidney transplants creates a necessity and a significant demand on any source of infant donors.

The Nature of the Problem

Given that the removal of organs from anencephalic infants seems to provide benefits for several groups of individuals, why is there such controversy?

Modern medical techniques have altered the conventional concepts of death. In Australia it is generally accepted that death is said to have occurred when there is irreversible cessation of circulatory and respiratory function or where there is irreversible function of the entire brain, including the brainstem.

In New South Wales⁹, Victoria¹⁰, Tasmania¹¹, South Australia¹², Australian Capital Territory¹³ legislative provisions have included this definition as being applicable for the purposes of the law of the State or Territory. In Queensland however, the definition of death in the Transplantation and Anatomy Act 1979¹⁴ is self referential and is therefore only to be applied for the purposes of that Act. For this reason there is no legislative definition of the term for the purposes of the general and criminal law under the Queensland Criminal Code.

Nevertheless, the courts have tended towards adopting the dual criteria of death for the purposes of the criminal law of Queensland. In *Machereek v. Steel*¹⁵ the English Court of Appeal essentially restated the legislative concept of death, where Lord Lane C.J.¹⁶ said that

6 F Ahmad 'Anencephalic Infants as Organ Donors: Beware the Slippery Slope' *Canadian Medical Association Journal* 1992 146:236-244.

7 *Supra* n.5.

8 *Ibid.*

9 *Human Tissue Act* 1983 s33.

10 *Human Tissue Act* 1982 s41.

11 *Human Tissue Act* 1985 s27A.

12 *Death (Definition) Act* 1983 s2.

13 *Transplantation and Anatomy Ordinance* 1978 s45.

14 Section 45.

15 [1981] 1 WLR 690.

16 At page 694.

there is only one true test of death and that is the irreversible death of the brain stem, which controls the basic functions of the body such as breathing. When that occurs it is said the body has died, even though by mechanical means the lungs are being caused to operate and some circulation of the blood is taking place.

The principles enunciated in *Malcherek v. Steel* have been echoed in the Court of Criminal Appeal of Queensland as being applicable and correct. In *R v. Kinash*¹⁷, Connolly J¹⁸ held that 'it was universally accepted by the medical profession that permanent death of the brain stem warrants termination of the artificial intervention'¹⁹. On the basis of general judicial authority and trend on the issue and the legislative provisions, the definition of death is seen to be universal in Australia²⁰.

The important factor with regard to anencephalic infants is that they are typically born with their brainstem functions intact and they cannot be declared dead at birth, since they retain cardiorespiratory function and brainstem function. Anencephalics are severely brain damaged and have a hopeless prognosis, but they are not brain dead. This has been recently reinforced in the case of an anencephalic girl in the United States, whose parents found out about her condition before birth, but decided to go ahead with the birth and donate the organs²¹. The US Supreme Court ruled that the baby was technically alive and until she was totally brain-dead, organs could not be removed. The baby died before the decision of an appeal was handed down. Even so, some living infant anencephalics, satisfying neither the dead-donor rule nor the strict criteria for whole-brain death, have been used as organ donors, by rationalising that the spirit if not the letter of the laws governing brain death was satisfied²². This practice has been deplored by some bioethicists as 'confusing a necessary condition ... with a sufficient condition'.²³

The cause of death in anencephalics has not been systematically studied and remains largely unknown²⁴. Death probably arises from cardiorespiratory failure, although it undoubtedly varies from case to case, depending on the severity of the anomalies of brain and other organ system functions²⁵. The effect of this is that by

17 (1992) Qd R 648.

18 At page 649.

19 Cases requiring an analysis of the definition of death under the Criminal Law of Queensland are generally concerned with s298 pertaining to issues of causation in murder.

20 In Western Australia no definition of death is included in the *Human Tissue and Transplant Act* 1982 nor is there any provision for the law of the Northern Territory. It is submitted however that the common law definition of death is equally applicable to these States, specifically Western Australia whose Criminal Code substantially mirrors the Queensland Code.

21 *The Courier Mail* 15th October 1992.

22 Holzegreve, Beller & Buchholz 'Kidney Transplantation From Anencephalic Donors' *The New England Journal of Medicine* 1987 316:1069-1070.

23 *Supra* n.4.

24 *Supra* n.5.

25 Frewen, Kronick & Kisson 'Anencephalic Infants and Organ Donation: The Children's Hospital of Western Ontario Experience' *Transplantation Proceedings* 1990 22:1033-1036.

the time brain death is declared, donor organs may be damaged by poor perfusion and be unsuitable for transplantation. This is not unique to salvaging organs from infants, but applies to all organ donors²⁶.

If anencephalic infants are to be viewed as a valuable source of organs for transplantation, questions now arise as to what strategies can be adopted for the collection of viable organs and what difficulties do these create.

Strategies for the Collection of Viable, Transplantable Organs From Anencephalics

Several medical strategies have been considered for the collection of viable organs from anencephalic infants²⁷. Briefly, these are —

- Use life-support systems at birth and remove organs as soon as possible, regardless of whether brain death has occurred;
- Use life-support systems at birth and observe the infant until brain-stem functions stop, then remove organs;
- Provide minimal care until non-brain death occurs, then place on life support until brain death occurs;
- Provide minimal care until non-brain death occurs, then remove organs.

Some of these strategies have clearly contributed to the controversy, as questions about their legitimacy and moral acceptability have been raised.

In order to address the legal requirements and/or ethical concerns associated with these strategies, several proposals have been made²⁸. They are —

1. Wait for death to be declared by traditional criteria
2. Redefine death specifically for anencephalics
3. Create an exception to the dead-donor rule to accommodate anencephalics within the existing definition of death
4. Consider anencephalics as non-persons

26 Mason & McCall Smith *Law and Medical Ethics* 1987 Butterworths London.

27 *Supra* n.2.

28 LS Rothenberg 'The Anencephalic Neonate and Brain Death: An International Review of Medical, Ethical and Legal Issues' *Transplantation Proceedings* 1990 22:1037-1039.

Critique of Proposals

1. Wait for traditional death

The option of waiting for traditional death before taking the organs is consistent with the procedure used for the collection of organs from other donors. The steps taken to sustain the transplantable organs are consistent with current practices with adult organ donors, whereby, when life can be sustained, the emphasis shifts from prolonging life to maintaining organ vitality for transplantation²⁹.

The infant is placed on vigorous life support to maintain the transplantable organs. The infant is then removed from the support for short periods at regular intervals to assess the cardiorespiratory function or brain function³⁰. When either is assessed to be irreversibly stopped, death is legally declared.

Thus, assuming death is diagnosed on accepted grounds and parental consent is obtained, organs could now be removed for transplantation. This has indeed been the practice in some situations³¹.

This 'wait until death' strategy has been used since 1987³². However, experience has shown that it does not seem to have been as worthwhile as initially anticipated³³. This strategy is not without its technical and ethical problems.

The problems of confirming brain death in children less than two months old and especially less than seven days old have been widely reported³⁴. Accepted clinical criteria for determining brain death in adults cannot be confidently applied to newborn infants. Vital signs are changeable and the prediction of irreversibility of brain function is unreliable³⁵.

One ethical issue raised by this strategy concern the life support of newborns solely for maintaining organs to be used for the benefit of others. This has been claimed to violate the dignity of the infant 'donor'³⁶. It may be argued that continued resuscitation is not ethically needed, since it is only being used to preserve the organs and the patient donor can derive no benefit from it. Standard treatment

29 Norris & House *Organs and Tissue Transplantation* 1991 FA Davis Company Philadelphia. Illustrative of this practice has been heard recently (*Courier Mail* 3 May 1995) where there was a controversy surrounding a Townsville doctor who removed the patients heart while cardiorespiratory functions continued via life support mechanisms, but brain functions ceased. This process ensured organ vitality for transplantation.

30 *Ibid.*

31 GJ Annas 'From Canada With Love: Anencephalic Newborns as Organ Donors?' *Hastings Center Report* 1987 17:36-38.

32 *Supra* n.1.

33 Peabody, Emery & Ashwal 'Experience With Anencephalic Infants as Prospective Organ Donors' *The New England Journal of Medicine* 1989 321:344-350.

34 Task Force on Brain Death in Children 'Brain Death Determination in the Newborn' *Pediatrics* 1987 80:293-297.

35 JJ Volpe 'Brain Death Determination in the Newborn' *Pediatrics* 1987 80:293.

36 JL Bernat 'Ethical Issues in Brain Death and Multorgan Transplantation' *Neurologic Clinics* 1989 7:715-728.

for an anencephalic infant not considered for organ transplantation is merely comfort care.

Balanced against this are the benefits to be derived. An anencephalic newborn is not competent to give consent and does not appear to be harmed by having life extended for a few days. However, he/she does not benefit from prolongation of life. A consequentialist, utilitarian approach would view the decision in terms of the action which would yield the greatest good and maximise societal welfare³⁷.

A second ethical concern relates to the violation of the Kantian mandate about the use of a person as a means to an end³⁸. In such a deontological analysis, the competing duties are compared. These duties include respect for the anencephalic infant, attention to the family's wishes, concern for the recipient, and regard for the legal requirements.

The courts have ruled on what duties are required on the issue of the sanctity of life and the treatment/non-treatment of severely disabled or brain-damaged infants³⁹. The law merely formalises what is morally of social importance. As Lord Chief Justice Coleridge has stated⁴⁰ "*It would not be correct to say that every moral obligation involves a legal duty; but every legal duty is founded on a moral obligation*". Lord Donaldson in a judgement relating to the mechanical ventilation of a gravely brain-damaged, four month old child, stated that "*even very severely handicapped people find a quality of life rewarding which to unhandicapped may seem manifestly intolerable ... but in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurable benefit, giving the fullest possible weight to the child's, and mankind's desire to survive*"⁴¹.

At common law the lawfulness of medical treatment conducted on mentally impaired children depends on whether the treatment is in the best interests of the patient, taking into account the gravity of the consequences of wrongly authorising the treatment⁴².

Walters and Ashwal⁴³ and Williams⁴⁴ argue that Kant in his categorical imperative could not have had 'non-self-aware' individuals in mind when formulating his theory since for a person to be autonomous and hence eligible to be treated

37 TL Beauchamp *Philosophical Ethics: An Introduction to Moral Philosophy* 1982 McGraw-Hill New York 1982.

38 I Kant *Groundwork of the Metaphysics of Morals* Translated by HJ Paton 1964 Harper and Row New York.

39 I Kennedy *Treat Me Right* Clarendon Press Oxford 1988.

40 *R v. Instan* (1893) 1 QB 453.

41 Law Report *Bulletin of Medical Ethics* November 1990 at 22-23.

42 In *In Re S* (1990) FLC 92-124 and *In re Marion* (1991) 1 FLC 92-193 these principles were relevant to the issue of consent in relation to proposed hysterectomy operations on intellectually disabled girls.

43 Walters and Ashwel 'Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues' *Hastings Center Report* 1988 18:19-27.

44 P Williams 'To Be A Person' *Hastings Center Report* 1989 19:41-42.

morally. Kant believed that person should be rational and capable of choosing moral actions. Therefore the applications of Kant's philosophy to anencephalic infants is going beyond his moral theory. If the infant is not an autonomous moral agent and not considered to be 'alive' while on the support systems, the Kantian objection to using a person as a means to an end is not violated⁴⁵. Davis⁴⁶, herself a spina bifida patient, argues strongly and convincingly against the need for rationality in order for one to be treated morally.

2. Redefine Death

Death is seen by many in society as an all-or-nothing truth. Many consider that the definition of death should not be whatever individuals want it to be, at that time. It should be independent of the purpose for which it is required.

Some philosophers suggest that there is no true definition of death, rather at any time, a definition of death is merely that which is accepted as social convention. It is created by society and exists to solve problems⁴⁷. Throughout history definitions of death have merely mirrored a consensus of society's views⁴⁸. The compatibility of 'socially-accepted' definitions of death and religious doctrine has been and remains an area of controversy, due to different interpretations of religious beliefs⁴⁹. Nevertheless, the definition of death is not arbitrary, even if it is subjective, reflecting society's values. Walters⁵⁰ argues that society is now ready to accept another change, specifically it is ready to accept a change in relation to redefining death in the case of anencephalics.

Green and Wikler⁵¹ have argued that death should be equated with the irreversible loss of cortical function rather than loss of whole brain function, as is required by current law. The brainstem controls 'vegetative' functions, that is it controls the integration of the functions of the major organ systems. The higher brain or cortical brain endows the individual with human qualities such as personality, consciousness and social interaction. The cortical function is thus responsible for 'personhood' and unique human values and is argued to be the brain function that is of moral importance⁵².

45 M Benjamin 'Anencephalic Infants as Sources of Transplantable Organs by the Ethics and Social Impact Committee, Transplant Policy Center, Ann Arbor, MI *Hastings Centre Report* 1988 18:28-33.

46 A Davis 'The Status of Anencephalic Babies: Should Their Bodies Be Used As Donor Banks?' *Journal of Medical Ethics* 1988 14:150-153.

47 N Frost 'Organs From Anencephalic Infants: An Idea Whose Time Has Not Yet Come' *Hastings Center Report* 1988 18:5-10.

48 LP Ivan 'Anencephalic Donors: A New Ethical Challenge for Clinical Neuroscientists' *Journal of Child Neurology* 1989 4:158-164.

49 *Supra* n.36.

50 JW Walters 'Yes — The Law on Anencephalic Infants as Organ Donors Should be Changed' *The Journal of Pediatrics* 1989 115:825-828.

51 Green & Wikler 'Brain Death and Personal Identity' *Philosophy and Public Affairs* 1980 9:10-11.

52 *Ibid.*

This argument suggests that if higher brain function is irreversibly lost, the individual ceases to be a person and should be considered dead. The moral person is dead. Under this definition, since the anencephalic lacks a functional cortex, he/she could be regarded as dead and a suitable organ donor, even though the body 'lives on' and functions by virtue of technological support devices. The anencephalic then is only technically and legally alive because the brain stem, and the brain stem only, continues to function⁵³.

While such a redefinition may have philosophical merit, it raises serious legal and social implications for other patients.

While the differences between anencephalics and those in a persistent vegetative state are reasonably clear, they are not great⁵⁴. In the desire to find other organ donors, groups such as those could be included in an expanded definition and such a suggestion has already been made⁵⁵. The higher brain definition also poses a threat to the senile elderly and the profoundly brain damaged⁵⁶. The potential for inappropriate application of this definition of death to clinical situations is clearly undesirable.

Death, in fact, could be redefined in whatever way maximises the greater good⁵⁷. However, such a utilitarian proposal encourages a redefinition whenever utility requires. Anencephalics or indeed unwanted person could then be 'defined away', it could be argued to serve the greater good.

3. Create an exception to the dead-donor rule within the existing definition of death

This is clearly a utilitarian move to place anencephalics in a special category — a *sui generis* — that is legally equivalent to brain death, so organs can be removed for the greater benefit. The justification is that anencephalics are unconscious, higher brain absent, facing eminent death and have no hope of recovery.

This special category in essence authorises the termination of the infants life once parents agree to the donation of organs. The burden is thus placed on the parents to agree to the ceasing of life of their child. The questions of unrestricted parents' rights to donate organs from their children under any circumstances and whether children are parents' property can be raised. These are beyond the scope of this paper, but have been discussed in the literature⁵⁸.

53 *Supra* n.2.

54 *Supra* n.2.

55 JM Stanley 'More Fiddling With the Definition of Death?' *Journal of Medical Ethics* 1987 13:21–22.

56 *Supra* n.2.

57 RM Veatch 'The Whole-Brain-Oriented Concept of Death: Can Organs Be Transplanted Before Brain Death?' *The New England Journal of Medicine* 1989 80:293–297.

58 B Franklin *The Rights of Children* Basil Blackwell London 1986.

Errors in diagnosis of anencephalics is another problem with this approach. As mentioned previously, malformations lie on a continuum and diagnosis is not always straight forward. The interest of the correctly diagnosed anencephalic may not be violated, given their condition. The real concern is the potential future patients who may be similarly categorised as 'brain absent', that is, other patients with related neurological defects, such as hydraencephaly, spina bifida infants and some microcephalics⁵⁹. The danger is the possible slow erosion of barriers to what are now unethical practices and desensitisation to ceasing life over time⁶⁰.

Once a special exception has been made for one group of patients, there is no reason why exceptions should not be made for other groups who currently have legal rights. If one can take organs from anencephalics, there is to some extent, no reason why they can not be taken from other groups with severe abnormalities, terminal illnesses or who are about to die, who are soon to be dead, who are as good as dead or are virtually dead⁶¹. How long will society keep anencephaly as a unique exception in the face of organ demand?

The inherent benefits of creating an exception to the dead-donor rule for anencephalics is that instead of two children dying, one is saved. The agony of the anencephalic's inevitable death is eased by another's life being saved. The reality of this comfort has been heard from Atie and Roel Goossen, who say the "their pain has been eased by knowing their son's death has saved other Australian's lives⁶². This report received front page coverage and the Goossen family's generosity and benevolence gained community support and approval. Depicted in this single image are the benefits to be gained from an almost hopeless and saddening occurrence of the death of one's child. Of course, as in any dilemma, one must equitably assess the benefits and possible detriment in creating an exception to the dead-donor rule for anencephalics.

4. Consider anencephalics as nonpersons

The anencephalic infant has no consciousness, no self awareness, no autonomy and no future life. Given this, Wilke and Andrusko⁶³ have argued that the anencephalic is a nonperson, a mere function, not a person in the legal and moral sense. This argument was expounded by those in favour of the redefinition of death to mean higher brain death. In fact, it has been a common denominator in the arguments put forward in support of many of the above options already discussed — conceding that the child is alive but removing the organs on utilitarian ground, changing the definition of death to accommodate anencephalics and creating a separate 'brain absent' category.

59 *Supra* n.1.

60 *Ibid.*

61 *Ibid.*

62 *The Courier Mail*, 16 October 1993.

63 Wilke & Andrusko 'Personhood Redux' *Hasings Center Report* 1988 18:30–33.

Such utilitarianism reduces the sole utility of the anencephalic to organ transplantation. This would appear to be the dismissal of the humanity of anencephalics. This clearly flies in the face of medical codes and social traditions requiring members of society to treat, care and respect each other as a person with intrinsic worth and rights⁶⁴.

Conclusions

In our culture there is a pluralism of views. Some issues are interminable, with both sides having valid points of view. Yet a decision has to be made, whether or not it can be fully justified. The donation of organs from anencephalic newborns is one such major ethical dilemma of medicine today, where decisions are difficult but needed.

This societal, moral and legal problem however, unlike others can not be considered as if it were an isolated one, since the solution will have implications for many other closely related problems. Morality is a system for guiding and judging behaviour. Hence, the social acceptability of the answers to a particular problem such as discussed in this paper, must be considered in relation to their acceptability as answers to many other problems.

The two ethical theories that dominate such moral disputes as anencephalic organ donation are those of Immanuel Kant and John Stuart Mill and these have been referred to at various points throughout this paper. Each depicts certain aspects of the moral issue and emphasises that every moral obligation does not involve a legal duty, but every legal duty is founded on a moral obligation.

Each of the four strategies for harvesting anencephalic organs discussed in this paper is fraught with moral dangers and legal and medical impediments. Despite the acknowledged demand for infant organ sources it remains that the law should not be treated like an axle, whereby if enough grease is added it may be twisted and turned to suit the needs of a select few. It has been said the 'necessity is the plea for every infringement of human freedom. It is the argument of tyrants'⁶⁵. If anencephalics are acknowledged as an appropriate source of organs, which categories of dying or impaired patients is next? Given the advancements in improving the effectiveness of prenatal screening for anencephaly, the question as to whether anencephalics are a valuable source of transplantable organs may be a moot one.

Traditional Western medical ethics are founded on the Christian theology which prohibits the taking of human life, irrespective of the benefits. However, it is still open to argument that even if we accept the distinction between biologic

64 *Supra* n.26.

65 William Pitt, the Younger.

and personal human life, is the killing of the nonpersonal, but living human for the sake of harvesting their organs to save the life of another justified?

Resources and ingenuity should be directed towards greater research to develop monitoring and maintenance systems that would satisfy existing ethical and legal mandates. Ways should be found to care for dying infants, including anencephalics, so that when death is declared they can become organ donors. Changes in the law and moral gymnastics of the type discussed in this paper will be as unnecessary then, as they are now appear to be undesirable.

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