

Use of anencephalic newborns as organ donors



Français en page 339

Organ transplantation for infants and children with life-threatening illnesses has become very successful. However, this success is limited by a serious shortage of suitable donor organs. A variety of approaches to improve organ donation rates have been undertaken in adults but these approaches cannot be applied widely to paediatric patients because of physical limitations governing organ suitability and size. These limitations caused widespread discussion in the late 1980s and 1990s about considering the anencephalic infant as an organ donor, including the possibility of altering the standard brain death criteria to apply to the anencephalic infant and of donation of anencephalic infant organs before death (1-5). The potential to save the lives of infants dying from cardiac, renal and liver disease, and the desire to give meaning and benefit to the anencephalic infant's family were presented as justification for changes in the medical standards and the law concerning death and organ donation from anencephalic infants (6,7). Official statements from the Canadian Paediatric Society (CPS) (1990) and the American Academy of Pediatrics (1992) affirmed that anencephalic infants were not appropriate organ donors and rejected arguments advocating modification of the medical criteria of brain death and legal standards of pronouncement of death (8,9). This updated CPS statement presents current information for clinicians supporting the previous CPS position that did not support the use of anencephalic infants as organ donors in the clinical setting.

ORGAN TRANSPLANTATION IN INFANTS

Organ transplantation is now an integral part of life-saving therapy for infants with serious illness, including cardiac, hepatic and renal disease. The increasing success resulting from improved surgical techniques and intensive care expertise, and progress in transplantation immunology and therapy have resulted in a serious organ donor shortage for infants. Due to organ size restrictions, this shortage has not been alleviated by strategies to increase donation rates or by increasing living related donation, as occurs in older children and adults.

The same ethical principles and medical criteria for transplantation in adults and older children apply to infants, either as recipients or as donors. Ethical principles require that the potential organ donor be declared brain

dead or pronounced somatically dead before organ donation using standard cardiorespiratory criteria – the 'dead donor rule'. The process of discussion must be consistent with the standards of surrogate informed consent (10). Parents, as the surrogate decision-makers for infants, must be fully informed of the risks to themselves, the potential infant donor and the recipient of involvement in the organ donation process. The benefits of saving another infant's life and of giving the death of their infant some spiritual meaning may influence parents to agree to the donation of their infant's organs. Similarly, most parents of dying infants may consider the benefit of organ transplantation to outweigh any risks. To avoid any subtle coercion, physicians involved in organ transplantation should not be involved in consent discussions with parents of potential organ donors. Physicians must be aware of the serious potential for parents to be coerced into organ donation. Ongoing evaluation of such cases should be undertaken to ensure that the benefits and risks to the infants, families and society are justified.

ORGAN DONATION FROM ANENCEPHALIC NEWBORN INFANTS

Anencephaly is a central nervous system abnormality that is characterized by congenital absence of the forebrain, skull and scalp. Some rudimentary forebrain tissue may exist and a functioning brainstem is usually present. Most anencephalic infants die within days or weeks without life-supporting interventions (2,7). One infant, 'Baby K', lived for 2.5 years as a result of aggressive life support (11).

Use of anencephalic infant organs for transplantation gained widespread publicity in the late 1980s after the Loma Linda Medical Centre reported a successful newborn heart transplant using a Canadian anencephalic infant, 'Baby Gabriel', as the organ donor. In 1989, Loma Linda reported a study (6) of 12 anencephalic infants who were supported with intensive care measures for one week to facilitate declaration of brain death. Successful organ donation did not occur from any of the infants. The study authors concluded that anencephalic infants could not be used as organ donors without legal and medical changes to regulate brain death and organ donation. At the time of the writing of this statement, these changes have not occurred.

Infants with anencephaly require the same respect for life given to other human beings.

As with other newborns, the standard medical criteria and ethical principles for organ donation and transplantation must be applied to anencephalic infants when they are considered as potential donors. Organ donation may only be considered if the anencephalic infant has satisfied the criteria for brain death or somatic death as applied to other human beings. Physicians should ensure that the same ethical standards applied to other organ donors are used for infants with anencephaly.

Experience from individual cases and the Loma Linda study identified specific problems with the process of organ donation from anencephalic infants under the current medical and legal standards (3,6). First, anencephalic infants will not usually satisfy the standard brain death criteria because of adequate brainstem function that maintains spontaneous respiration and heart rate after birth. Second, by the time brain death or somatic death has been declared, the organs will have undergone ischemic damage, making them unsuitable for transplantation. This occurs because cardiovascular and respiratory functions deteriorate gradually in anencephalic infants before a terminal event. Third, the use of life support does not improve the chance of successful organ donation from anencephalic infants. While organ function may be maintained with life support, as brainstem function deteriorates, multisystem organ failure develops before sudden death.

In 1994, the American Medical Association (AMA) Council on Ethical and Judicial Affairs stated an opinion supporting the use of anencephalic infant organs for transplantation before death of the anencephalic infant, as long as parental consent requirements were met and other safeguards were satisfied (12). This radical departure from the 'dead donor rule' was subsequently supported by an AMA Council report (13) in 1995 explaining the rationale for this opinion. The AMA Council report expressed the hope that public consensus would result in changes to the law to allow organ donation from living anencephalic infants. Such a development in public opinion has not occurred due to legal and ethical concerns and recent medical developments.

Ethical concerns opposing organ donation from living anencephalic infants include the following (14,15):

- application of similar arguments in favour of organ donation from other seriously brain-damaged living patients;
- serious risk of loss of public trust in transplantation programs;
- serious deleterious effects on families and staff involved in such cases; and
- risk of loss of public respect for the intrinsic value of all human life.

The current AMA Policy (16) affirms the 'dead donor rule' but supports the use of medical therapy and mechanical ventilation to sustain organ viability until death is declared.

New medical developments have greatly decreased the potential benefit from using anencephalic infants as organ donors. First, the widespread use and improved diagnostic accuracy of routine prenatal ultrasound has been associated with increased prenatal diagnosis of anencephaly and subsequent high rates of pregnancy termination. Second, folate fortification of food and preconceptual folate supplementation has significantly decreased the incidence of neural tube defects including anencephaly. As a result, the number of anencephalic infants born at term has decreased so much that the potential benefit from attempts to use their organs for transplantation is minimal (17-20). Finally, the major indication for neonatal heart transplantation, hypoplastic left heart syndrome, is now commonly treated by Norwood staged surgery rather than by transplantation, in part because of organ donor shortage, but also because of long-term concerns about morbidity after transplantation (21).

In recent years, discussion of organ donation from anencephalic infants has diminished with the exception of occasional case reports and theoretical discussion (22-24).

RECOMMENDATIONS

- Organ donation from anencephalic infants should not be undertaken due to the serious difficulties surrounding the establishment of brain death in these infants and the lack of evidence to date supporting successful organ transplantation.
- There should be no alteration or modification of standard infant brain death criteria to include infants with anencephaly.
- Families who request the opportunity to donate organs from their infant with anencephaly should have information and educational material provided that explain why this practice is not supported. The option of tissue and stem cell donation should be discussed using the ethical principles and medical practices applied to other donors.
- The practice of using medical therapy and mechanical ventilation to maintain organ function pending the declaration of death in infants with anencephaly is not supported.

ACKNOWLEDGEMENTS: This position statement was reviewed by the CPS Fetus and Newborn Committee during development.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.