Establishing the possibility of neonatal and paediatric organ/tissue donation

There are increasing demands for donated organs/tissues and a heightened awareness amongst the medical and nursing professions regarding recognition of potential donors and obtaining consent. This article explores the possibility of donation from neonates and highlights an innovative practice that has so far proven to be successful. As transplantation in newborns is in its infancy and long term results have yet to be evaluated, physicians performing such transplantations must evaluate the benefits, problems and costs to the infants, their families and society.

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Key points

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- 1. Organ and tissue donation is regularly discussed and approached within adult ICUs and A&E departments across the UK, but is not a subject addressed within neonatal intensive care.
- 2. Due to the inability to successfully determine brain stem death in babies under the age of two months, heart beating donation is not an option that can be considered in this population.
- 3. However above 32 weeks' gestation the heart valves of babies who have died can be donated for transplant.
- 4. When offering this service, it is important to inform parents of their options, without pressurising them to donate or making decisions for them without their knowledge.

The achievement of successful organ donation has led to the extension of life for many people. With the advancement of medical technology, improved methods of providing artificial ventilation and respiratory support as well as organ preservation, compatibility and immunosuppression, more people are being given the opportunity to experience transplantation and the chance to not only lengthen, but also improve their quality of life.

In the last five years there have been a total of 414 paediatric organ donors in the UK and Ireland and a total of 1104 paediatric patients have received transplanted organs. This success has led to an increase in demand for donor organs and a widening gap between the number of children waiting for transplants and the number of available organs, resulting in a significant number of children continuing to die whilst waiting for transplantation. Organ donation is clearly not keeping pace with the rapidly increasing demand, it is therefore essential to maximise the potential number of organs available from the existing potential donor pool. The majority of children who are potential donors have suffered traumatic head injuries, most commonly as a result of road traffic accidents or the small number of children who are diagnosed as brain dead following a spontaneous cerebral haemorrhage.

The criteria and ethical principles that apply to organ transplantation involving children and adults also apply to the newborn, as either recipient or potential donor. The stakes for recipients and their families are high; therefore, there is considerable obligation to ensure that the

family understands the limited medical knowledge about both the risks and benefits of the procedure. Given that transplantation in newborns is innovative, that our knowledge of the intermediate results is limited and that the long term results have yet to be evaluated, physicians performing such transplantations must evaluate the benefits, problems and costs to the infants, their families and society. The evaluation should also include the families of successful and unsuccessful potential donors and of recipients. Whenever a child is considered to be a potential organ donor the possibility should be discussed with the parents in order to give them the opportunity to consider this option. Organ or tissue donation can be a positive option and can also be a comfort at a time of great distress. By not offering this option to donate, healthcare professionals may be depriving families of the opportunity to find comfort during their time of grief.

The author is an Advanced Neonatal Nurse Practitioner in a busy level 3 neonatal intensive care unit in which the death of some babies is inevitable. The effect that the death of a baby has on parents and staff is immense. Parents are obviously distraught at this very distressing time and require much support and guidance. In the author's hospital, organ donation in adult intensive care is an issue that is regularly considered due to the employment of a dedicated transplant coordinator and team. At the beginning of this study the author believed that if the parents of terminally ill, newborn babies could get some comfort and consolation from the death of their baby by offering



their child's organs or tissue for transplant, then the development of such a practice would be of benefit to so many (FIGURE 1).

At the outset there was no such service offered to parents within the UK, but cases of donation from anencephalic infants were identified in the USA and Canada. This obviously raised a great deal of legal and ethical questions and as the UK tends to abort fetuses diagnosed antenatally as anencephalic, these infants are not considered further in this article. Instead the possibilities of organ donation from babies, especially neonates, are investigated as well as at what gestation donation is an option. The ethical and legal positions of this emotive subject are discussed and the benefits and disadvantages to the donor, recipient and families are identified as well as how the sensitive issue of organ donation from the death of a baby or young child can be approached and consent obtained. As a result of the study tissue donation is now an option that is being addressed in the author's unit and the process and development of such a service is described.

Definition of death

Historically, before the development of neurological criteria for determining death, it was generally accepted practice that death was the cessation of circulation and respiration¹. As technological complexity in critical care advancements continue, the concept of death defined by neurological criteria has emerged and evolved. It is now generally regarded by the Royal College of Physicians (RCP)² that the definition of death is the irreversible loss of capacity for FIGURE 1 Sophie is a hypoplastic left heart case who had homograft for stage one and stage two operations. She is now an active eight year old. *Photo courtesy of Oxford Heart Valve Bank.*

consciousness, combined with irreversible loss of the capacity to breathe. The irreversible cessation of brain stem function (brain stem death), whether induced by intracranial events or the

result of extra-cranial phenomena such as hypoxia, will produce this clinical state and therefore brain stem death equates with death of the individual. The British Paediatric Association (BPA) supported by the Council of RCP in their report in 1991³ suggested that in children over the age of two months the brain stem death criteria should be the same as those in adults, although the precise techniques used may need to be adapted slightly, particularly in very small children. Diagnosis of brain stem death prior to two months is unreliable, but at the clinician's discretion: below 37 weeks' gestation the criteria cannot be applied. The working party established by the Council of BPA to establish criteria for the diagnosis of brain death in infants and children recognised that babies above 37 weeks' gestation to two months of age may suffer coma for a variety of reasons, the most common being hypoxic-ischaemic encephalopathy, especially when the cerebral insult occurred *in-utero* or at the time of birth. These infants are very difficult to assess and it may not be possible to demonstrate sufficient structural brain damage as there may also be multi-system failure. Therefore the concept of brain stem death is inappropriate for these infants and decisions on whether to continue intensive care should be based on the assessment of the likely outcome of the condition after close discussion with the family.

With the development of ventilation and other techniques for maintaining life, breathing and cardiac function can be maintained by artificial means. This allows for the recovery of materials for

transplantation from bodies of persons who have been diagnosed dead after the brain stem has ceased to function, but in whom cardiorespiratory function is maintained (known as the 'beating heart' donor). This concept is difficult for many to comprehend and opponents to the practical use of the concept of brain stem death suggest that while the patient may be doomed to die he is not actually dead⁴. There appears to be disparity regarding the meaning of death, implying that there are different types of dead: clinically dead or legally dead. English law has alleviated this problem and the courts have adopted as part of law the proposals of the brain death criteria set out by the Conference of Royal Colleges (1976)⁵ for the diagnosis of death further established by Re A (A Minor) [1992]⁶ and Re TC (A Minor) [1994]⁷.

The main premise on which the colleges have argued the propriety of accepting brain stem death as death of the person has always been the claimed inevitability that when brain stem function ceases the heart will stop beating shortly thereafter. In paediatrics, especially neonates, there is no physiological reason why this should happen because infants generally develop respiratory collapse and their healthy heart carries on beating for some time after respiratory function ceases⁸.

Consent to donation

In 1995 a survey by the UK Transplant Coordinators Association, the British Association of Critical Care Nurses and MORI identified that the single most important factor in increasing the number of organs donated, is to ensure that relatives of potential donors are always approached. They also highlighted that 12% of families of patients in whom death was verified by brain stem tests were not approached about donation⁹. Whilst they state that relatives should always be approached by someone specifically trained for the purpose, it is worth remembering that under Article 8 (The right to respect for private and family life) of the Human Rights Act (1998)¹⁰ the next of kin have a moral and legal right to know they can donate organs and tissue if they so wish.

In 2000, the Bristol Royal Infirmary and Liverpool's Alder Hey Hospital in the UK were among many hospitals exposed as having retained children's organs and body parts following post-mortem examinations. For the majority, the families of the deceased children were

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unaware of this, as the law (Human Rights Act 1998)¹¹, was somewhat vague about the need for relatives' permission. Even the medical profession did not know the scale of this practice until a census was ordered by England's Chief Medical Officer (CMO). In 2001, this task uncovered more than 54,000 organs, body parts, stillborn children, or fetuses that had been retained since 1970¹². Similar findings were made in Wales, Scotland, and North-ern Ireland. The first recommendation from the CMO was that the law must be amended with immediate effect

'consent must be sought from those with parental responsibility for the retention of tissue or organs from post-mortems on children beyond the time necessary to establish the cause of death'.

Subsequently a far broader programme of legislative reform covering all aspects of human material, including transplantation, was proposed by the DOH¹³. In the wake of scandals about the unauthorised retention of organs following post-mortem examination¹², the issue of valid consent (or the lack of it) has returned to the forefront. Emphasis is put on obtaining explicit authorisation from the patient or family prior to any medical intervention, including those involving the dead.

Although the controversies in the UK arose from the retention of human material for education or research rather than therapy, concern has been expressed that public mistrust could also adversely affect organ donation for transplantation. Surveys carried out after the events at Alder Hey showed an increasing support for a shift to presumed consent (opting out), indicating that the public clearly perceives differences between giving consent for organs to be used for transplantation and organs being retained for research without consent. In fact UK Transplant recorded an increase in donors aged under six years of age (five in 2000, 14 in 2001) and increases in registrations to the organ donor register.

The United Nations (UN) Geneva

FIGURE 2 Matthew, pictured just before his heart valve transplant at nine days old. *Photo courtesy of Oxford Heart Valve Bank.*

Convention on the Rights of the Child (1989)¹⁴ has three key Articles that underpin health decision policies with regard to discontinuing life support treatment for children. These Articles cover the availability of rights to all, that the best interests of the child be of primary consideration and the children's views be taken into account in all matters affecting them. The convention was endorsed in 1991 by the British government covering the fundamental nature of the Children Act 1989¹⁵. The respect for children's rights through the UN Convention is one of the fundamental principles outlined by the Royal College of Paediatrics and Child Health in their ethical framework for 'withholding or withdrawing life-saving treatment in children' (1997)¹⁶. This framework defines five situations when withdrawing or withholding treatment may be considered appropriate. It stresses that these decisions should never be rushed, that rigid rules guiding decisions should be avoided and that all available evidence must be consulted.

Evolution of tissue donation in Hull

This study aimed to determine whether organs from neonatal sources could be successfully obtained and used for

Solid organs		Tissue donors	
Heart	> 35 days of age	Heart valves	> 32/40 weeks
Liver	> 35 days of age	Corneas	> 1 year
Kidneys	> 6 months	Costal cartilage	> 10 years
Lungs	> 5 years of age	Bone/skin	> 16 years
Pancreas	> 8 years of age		

TABLE 1 The age at which children can donate organs or tissues.

transplantation. Although it became apparent that neonatal organ donation was not currently possible (TABLE 1), heart valve donation did appear to be a feasible option (FIGURE 2).

Healthcare professionals have a moral and legal right to offer advice and support to parents in all aspects of care including the possibility of donation after death. A situation occurred on the unit where parents wished for their dying baby's organs and tissues to be offered for donation, but at that time the resources or knowledge to offer that service were not available. The system failed these parents, but the author passionately believes it is important that other parents who may feel the same are not refused this service in the future.

Initially, the author liaised closely with the adult transplant co-ordinator for the trust to increase her knowledge of the process and indeed establish if there was a need that could be integrated into the unit. While the numbers of babies above 32 weeks' gestation that die in the author's unit is relatively low (approximately 2-3 per year) heart valve donation was still a possibility. Questionnaires were sent to each member of staff to identify their current knowledge and to establish if they would be supportive of implementation of such a project within the unit. Of the 74 questionnaires circulated 35% were returned. Of those, 95% expressed a wish to be trained and informed of ways to handle such requests from parents. These training sessions are ongoing and include communication skills, bereavement counselling and knowledge of tissue donation.

Posters and leaflets designed by the National Blood Service (NBS) specific to



FIGURE 3 Matthew has since had a second heart valve transplant and, as is evident from the photograph, continues to thrive. *Photo courtesy of Oxford Heart Valve Bank*.

tissue donation are now visible in parent areas in order to raise awareness of heart valve donation and a flow chart has been established so that staff have ready access to the correct procedure to be followed should the situation arise.

As with any implementation of innovative practice, audit is necessary and will be established over time. A tissue donation service has now been established and is available to parents, with staff trained and happy to approach parents about heart valve donation, should they wish.

The project has been established for a year now and until recently it was the only one of its kind in the UK. Since full implementation there have been two babies that have fitted the criteria for donation and of those, one successful heart valve donation.

Extension of the service could benefit other areas that require a sensitive approach to offering donation. Offering heart valve donation to those parents who undergo the devastating experience of stillbirth, may enable them to find some comfort in knowing their pregnancy was not in vain.

Donation facts

There are four forms of donation:

 Heart beating donation – the patient has to be certified 'brain stem dead' and organ retrieval is carried out whilst cardiorespiratory support is maintained

- Non-heart beating donation treatment is being withdrawn and the patient ceases breathing and cardiac function
- Tissue donation can take place up to 24 hours after death. One tissue donor can help up to 50 people
- Live donation e.g. blood, kidneys etc Exclusions for donors include:
- HIV
- CJD
- Systematic infection
- Malignancy
- Degenerative neurological disorders
- Age is an exclusion in some but not all the oldest donor of corneas was 103 and the oldest recipient 104
- Heart valves below 32 weeks' gestation

It is important that the parents are aware that the body has to be in the refrigerator within six hours of death, (this may cause some concern for some who feel they really don't want to let their baby go and wish to remain with their baby as part of their grieving process). A pathologist is required to remove the heart. The whole heart has to be removed and the remainder is not returned to the body. Retrieved tissues remain in quarantine until all information regarding the donor and the recipient is available and has been reviewed.

Conclusion

The single most important factor so far identified in increasing the number of organs donated, is to ensure that the relatives of potential organ donors are always approached, and approached by someone specifically trained for the purpose.

At the beginning of this work the author set out on the quest to discover whether organs or tissues from neonates could be used for transplantation, when there is no hope of their own survival. It is apparent that there are still many questions to answer and a need for further research into this area of medicine, but with dedication and commitment, neonatal healthcare professionals can offer a service to parents, if they wish to consider donation. Hopefully, with advancing neonatal technology in the next decade this area of medicine could help to ameliorate the ever increasing disparity between supply and demand of suitable organs and tissues for transplantation.

Without the participation of the public, transplantation and donation could not

exist, without the gift of organs or tissues many people will continue to die unnecessarily (FIGURE 3). Whilst it is a very emotive situation and one difficult for healthcare staff to address at a very distressing time for the parents or relatives of babies and children, it is crucial that staff are given the appropriate training and knowledge in order to be able to manage the process compassionately and professionally. The question that needs to be asked is: "Is it unethical not to ask?" Before any change to the system can be considered there needs to be certainty about the support of the general public and healthcare professionals. It is crucial that public confidence is maintained as this will undoubtedly lead to an increase in the availability of donated organs/tissues, always remembering that the morally correct decision, may not be the one that increases donor numbers.

It is time to give parents the opportunity to make an informed choice about what becomes of their dead baby's body and stop presuming that tissue donation is restricted to patients in adult ICUs or A&E departments.

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