

The current status of neonatal organ donation in the UK

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Solid organ transplantation provides life-saving treatment for infants and children with liver and cardiac failure, and is the best treatment for end-stage renal disease. In the UK in 2012/2013, 25 infants (<1 year of age) received organ transplants comprising four heart, 17 deceased donor liver and four living donor liver transplants, and as of January 2014, five infants were on the liver transplant waiting list and three were awaiting a heart transplant (personal communication with National Health Service Blood and Transplant (NHSBT)). While infants form only a very small minority on the active transplant waiting list, they are at a significantly higher risk of mortality, with 31% of infants on the cardiac transplant waiting list dying before receiving a transplant.¹ Furthermore, infants have the highest mortality of all patients on the liver transplant waiting list.² The principle reason for this excess mortality is a lack of suitable infant donors. Given that over a third of all paediatric deaths in the UK occur in the neonatal period,³ expanding organ donation in the neonatal population would address this imbalance as well as improving the supply of organs for older children on the transplant waiting list.

Currently in the UK, organ donation is not permitted from brain-dead infants <2 months of age. This is due to the current guidance on the diagnosis of brainstem death (BSD) which states that it is rarely possible to confidently diagnose BSD in infants between 37 weeks' gestation and 2 months of age, and that before 37 weeks' gestation, the diagnosis of BSD is inappropriate.^{4–5} However, this guidance has not been updated since 1991 and is at odds with current practice in other countries such as USA,⁶ Australia, Canada and many European countries, who accept the concept of BSD and organ donation in infants. We, therefore, have the rather perverse situation whereby

infants in the UK can receive heart transplants donated from infants in other European countries but cannot themselves be donors. Over recent years, this disparity has been highlighted by others^{7–8} and, as such, the guidance relating to brain death determination in infants is currently under scrutiny by both the Royal College of Paediatrics and Child Health and the UK Donation Ethics Committee. This is important as a recent study suggested that up to 13% of babies dying in a UK specialist neonatal unit between 37 weeks' gestation and 2 months, theoretically, could fulfil BSD criteria and become donors, if it were not for current restrictions.⁹ Hopefully, expected changes in guidance will allow this potential expansion of the donor pool to be realised in the near future.

The argument for pursuing this avenue is that donation after brainstem death (DBD) provides the best quality organs for transplantation. There were early concerns about increased risk of graft thrombosis and poor long-term graft survival of organs from young paediatric donors. However, recent studies have demonstrated good clinical outcomes of en-bloc renal transplantation from small paediatric DBD donors, including newborns and infants.^{10–15} Furthermore, favourable outcomes of liver transplantation from very small paediatric donors have been reported¹⁶; indeed in one large series of liver transplantation, donor age <1 year was correlated with improved recipient survival compared with adult donors.¹⁷ Infants undergoing cardiac transplant, the majority of whom receive hearts from infant donors, have the best survival of all paediatric cardiac transplant recipients.¹⁸ This success has encouraged clinicians to expand the use of organs from neonatal and infant DBD donors. A recent report describes successful multivisceral transplantation, including stomach, duodenum, liver, pancreas, spleen and small intestine, from a neonatal donor to a 3-month-old recipient with intestinal and liver failure secondary to midgut volvulus.¹⁹

One approach to circumvent the issues with the diagnosis of BSD in neonates is to use organs donated after cardiac death (DCD). Here, organs are procured after determination of death by cardiac

asystole, typically following the withdrawal of life-sustaining treatments on the grounds of futility. Recent studies have explored the potential for DCD organ donation in neonatal intensive care units. Charles *et al*⁹ recently reported the potential for neonatal organ donation from a single tertiary/quaternary UK neonatal unit. Over a 6-year period, they identified 34 potential DCD donors, representing 40% of all deaths over the time period. Labrecque *et al*²⁰ identified 16 eligible DCD organ donors from 192 deaths (8%) in three neonatal units over a 2-year period. Potential transplant organs from these donors included 14 livers, 9 en-bloc kidneys and 10 hearts. Similarly, Hanley *et al*²¹ identified 42–57 potential en-bloc kidney donors, depending on acceptable warm ischaemic time, from 609 deaths (7%–9%) over 10 years from a single neonatal unit. The same group also explored DCD cardiac donation, identifying five potential heart donors from 266 neonatal deaths over a 5-year period.²² Very encouragingly, in recent months, neonatal DCD organ donation has been realised for the first time in the UK, with three donors <4 weeks of age over the 12 months prior to June 2014 (personal communication with NHSBT). Hopefully, this effort can be sustained, allowing further expansion of the programme.

One issue with DCD organ donation is the period from withdrawal of care to cardiorespiratory death, particularly where associated hypotension results in potentially damaging functional warm ischaemia. However, it has been shown that the median time from withdrawal of care to asystole in neonates was 30 min,²³ further demonstrating the suitability of the neonatal population as DCD donors. Although the experience of transplanting organs from neonatal and infant DCD donors is limited, there are reports of successful cardiac,²⁴ lung,²⁵ liver²⁶ and kidney transplantations.²⁷ At the end of 2013, the first en-bloc kidney transplant from an infant donor in the UK received widespread media coverage.

However, there is ongoing controversy surrounding DCD donation, particularly in children. The protocol for the DCD cardiac transplants described above, controversially, only included a 70 s standoff period between asystole and commencement of retrieval.²⁴ In the UK, the current minimum standoff period for DCD donors is 5 min. The cardiac study raises important ethical considerations as to how soon death can be confirmed following asystole. There are also issues about where withdrawal of care should take

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place. To reduce the time delay between cardiac death and retrieval, optimising organ recovery, withdrawal in the operating theatre suite is preferable. However, withdrawal on the neonatal unit provides a familiar and supportive environment for parents at a highly distressing time. It is also important that parents are aware of the risk of failed DCD donation, whereby the interval between the withdrawal of care and cardiac death is too prolonged to make organ retrieval feasible.

Alongside the issues specific to DCD donation, other matters relating to neonatal organ donation as a whole merit discussion. Many clinicians may feel that encumbering families who are already grieving with the additional emotional burden of organ donation is inappropriate. However, the counter argument is that we should be giving the opportunity to parents who want their baby to become an organ donor. What is unknown is whether neonatal organ donation influences the emotional and functional outcomes of bereaved parents for better or worse. Finally, there have previously been concerns about the difficulties clinicians may find in balancing the conflict of interest between providing optimal end-of-life care and facilitating organ donation, which benefits a remote child to which they do not have a direct duty of care. However, the development of Specialist Nurses in Organ Donation in the UK has done much to address this by providing detailed knowledge and expertise to lead the donation process in collaboration with the clinical team.

In conclusion, the implementation of neonatal organ donation is feasible, and good outcomes of transplants from neonatal donors have been reported. Given the high waiting-list mortality of infants awaiting transplants, it is very welcoming that some of the barriers to neonatal organ donation in the UK have been overcome and DCD donations have been achieved in recent months. However, there remain a number of unresolved issues and this will require fundamental attitudinal, organisational and legislative changes. Coroners will need to be involved in this process to ensure they are willing and able to help facilitate donation, even in cases where a coroner's

inquiry may be needed. Neonatal staff will require education in counselling of parents, the donation process and certification of brain death. Transplant retrieval and implantation teams will need to overcome the psychological and technical difficulties posed by very small donors and recipients. However, the evidence suggests this is a challenge worth pursuing further.

Acknowledgements The authors would like to thank Mark Jones, Senior Statistician at NHS Blood and Transplant, for providing the data on the UK infant waiting list, donors and transplants.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.



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To cite Wright JCE, Barlow AD. *Arch Dis Child Fetal Neonatal Ed* 2015;100:F6–F7.

Received 26 June 2014

Accepted 21 July 2014

Published Online First 11 August 2014

Arch Dis Child Fetal Neonatal Ed 2015;100:F6–F7.

doi:10.1136/archdischild-2014-307053

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