Neonatal and infant organ donation: a challenging concept?

Donation from neonates is a relatively new and developing concept and the challenges that this can bring are seemingly large. Working collaboratively to develop strategies for specialist teams in conjunction with bespoke policies in clinical areas will facilitate greater opportunities for organ donation for families facing the death of their baby. In this article, the reasons for donation challenges are explored along with discussion of how teams can be supported to realise the potential in this area.

Angie Scales
RSCN, RGN
Lead Nurse Paediatric and Neonatal Donation and Transplantation, NHS Blood and Transplant
angie.scales@nhsbt.nhs.uk

Keywords

organ donation; transplant; neonate; SN-OD

Key points

Scales A. Neonatal and infant organ donation: a challenging concept? *Infant* 2018;14(1): 14-17.

1. There is significant potential for neonatal donation across the UK.
2. NHS Blood and Transplant (NHSBT) is committed to supporting the development of donation in paediatric and neonatal areas.
3. The NHSBT strategy sets out to improve the donation and transplantation pathway to ensure safe and optimal transplantation.
4. Specialist nurses for organ donation liaise between families and clinical and specialist teams to ensure the smooth running of the donation pathway.

In 2008 the organ donation taskforce set out a bold series of recommendations for increasing donors by 50% over a five-year period.[1] In achieving this, the UK steered towards providing a world class organ donation service, this being the focus of the subsequent strategy *Taking Transplantation to 2020*.[2]

Paediatric donation was not specifically considered in the taskforce recommendations[3] and donor numbers from those under 18 years of age have been static over the last ten years.[4] Although a call to consider donation from neonatal patients has been made for several years,[3,5,6] it is a concept only recently considered by the neonatal and paediatric intensive care units looking after infants at the end of their lives. NHS Blood and Transplant (NHSBT) now recognises both the potential for donation from these infants and the challenges that donation in neonatal and paediatric areas presents; bespoke strategies are beginning to be explored in greater depth.

Why now? The current picture

The call for neonatal donation is not new.[3,5,6] With the drive to achieve higher rates of donation in the UK and to address the shortage of organs for transplantation, specialist nurses in organ donation (SN-OD) and clinical teams have been striving to offer this opportunity. Anecdotally, media publicity from high profile cases has had the effect of enabling families to increasingly request donation as an option when facing end of life care choices for their child.

Developments in transplantation techniques now enable utilisation of organs that would previously not be considered possible, including innovations in en-bloc kidney transplantation (transplanting both kidneys into a single receiver using the donor aorta and vena cava as arterial and venous conduits)[7-9] and the development of hepatocyte programmes as a bridge to transplantation in children with liver failure.[10]

At the request of the Academy of Medical Royal Colleges (AoMRC), the Royal College of Paediatric and Child Health (RCPCH) reviewed the guidance for neurological determination of death in infants less than two months of age. This guidance was published in April 2015.[11] Prior to this, donation following circulatory determination of death (DCD) was the only option for infants less than two months of age.

It is now possible to determine death by neurological criteria in infants from 37 weeks gestational age (including corrected gestational age) to two months post term, although this is not without challenges as it is a new concept for this age group and for the neonatologists and neonatal units caring for such infants. Arguably, the defined criteria bring clarity to cases where the neurological criteria are met, thereby opening up the potential for donation following neurological determination of death (donation after brainstem death, DBD) and increasing the number of organs per donor that can be transplanted. The use of the guidance, however, is not widespread and involves an element of training, support and practice sharing to build confidence and knowledge among clinicians.

Paediatric organ donation

UK consent rates for paediatric organ donation fall below the national average for the adult population and paediatric donation rates have not seen the same increase as the overall population. Numbers have remained relatively static over a ten-year period (**FIGURE 1**).[4]

Donation from infants

The organ donation rate in infants below six months of age remains small but is increasing, largely due to DCD (**FIGURE 2**).[4]

The transplantation process and paediatric data

Identifying potential donors and referring them to the specialist team is the first step in the transplantation process (**FIGURE 3**). This establishes suitability for donation and the options for approaching the families of potential organ donors.

Data from paediatric units in 2015-16 showed wide variation in practice across all elements of the transplantation process.[12] Consent for organ donation remained lower in paediatric than adult populations in 2016-17:[4,13]

- paediatric DBD = 65% of families approached gave consent, adults = 69%
- paediatric DCD = 28%, adults = 59%.

Consent for organ donation is widely regarded as the element of the donation pathway most in need of improvement and family refusal rates are the biggest single obstacle to organ donation in the UK. Improvement of consent rates is rightly seen as a key priority in increasing donor numbers but more research is needed to fully understand the challenges of consent in families of paediatric patients.

Paediatric transplantation

On 31 March 2017 there were 172 children waiting for transplants; an increase from 165 at the same time the previous year. Of these:[4,13]

- 80 (46.5%) sought renal transplants
- 39 (22.5%) cardiothoracic
- 46 (27%) liver
- 7 (4%) intestinal.

The commitment to provide the highest number of organs in the best possible condition is part of a key strategy for NHSBT. The strategy sets out to address the utilisation of all organs retrieved for transplantation via improvements across the donation and transplantation pathway. It is the responsibility of the transplanting centres and NHSBT to ensure safe and optimal transplantation of as many organs as possible.[14]

There is often the assumption that organs from children go to other children. This is sometimes the case (particularly where organs need to be matched to size, eg cardiothoracic organs); but not always. It is important to remember that the matching and offering of organs is carried out according to strict criteria.

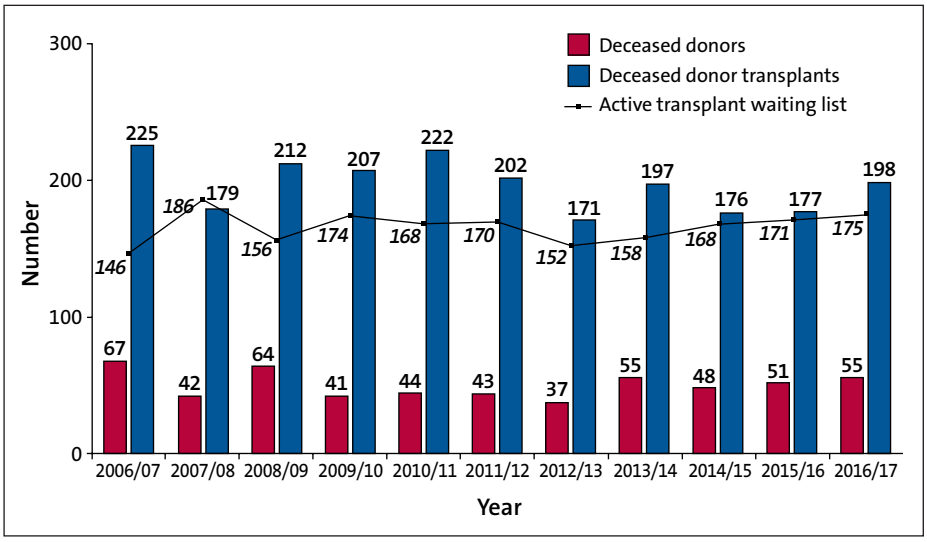

FIGURE 1 A graph showing the number of deceased paediatric donors, deceased donor transplants and the active transplant waiting list for <18 years of age in the UK, 1 April 2006 to 31 March 2017 (as of 8 May 2017) for all organs.[4]

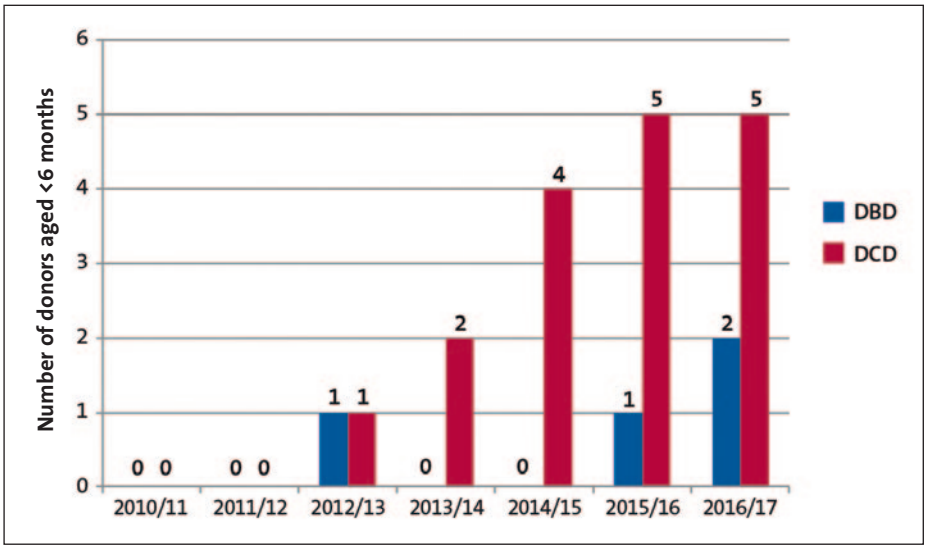

FIGURE 2 Donors aged less than six months by financial year and donor type, 1 April 2010 to 31 March 2017.[4] Key: DBD = donation after brainstem death, DCD = donation after circulatory determination of death.

1. Identification and referral of potential donor
2. Gaining consent and authorisation from a donor family
3. Donor optimisation*
4. Organ retrieval
5. Organ transplantation

FIGURE 3 The transplantation pathway. *Providing the highest number of donor organs in the best possible condition through optimisation of donor physiology.

The potential for donation from infants

Charles et al first demonstrated that there might be a potential for donation in greater numbers in the UK than previously considered. The single centre retrospective study of neonatal organ donation in a children's hospital analysed data over a six-year period and identified potential donors in up to 54% of deaths.[15] Furthermore, an informal auditing project by SN-ODs in

neonatal units appears to indicate that there are a small number of cases from each unit (unpublished work) which could amount to a significant number of potential donors across the UK.

There is ongoing work in the NHSBT National Organ Donation Committee Paediatric Subgroup to establish relevant data regarding the true potential for donation from NICUs. Potential donor audit data are gathered for critical care areas and emergency departments across the UK but at present data for NICUs are not collected in the same way and, although approximately one third of units are contributing data, the dataset for potential neonatal donation across the UK is incomplete. Work is being carried out to address this. Clarification of potential donor audit data is important in establishing clear information regarding actual potential, which can then guide practice and support strategic development of donation and transplantation programmes.

The role of the SN-OD

The specialist nurses provide a 24-hour service across the UK to support and facilitate organ donation from initial identification by clinical teams, determination of suitability, consent and then retrieval of accepted organs for transplantation. They are skilled in discussing donation options with families and providing support throughout the entire process for both families and clinical teams. Liaison between clinical teams and specialist teams is critical for the smooth running of the donation pathway.

Why are there challenges in donation?

Recent (unpublished) work by NHSBT with stakeholders suggests that there are many reasons why donation and transplantation present challenges in paediatric and neonatal areas of practice.

The nature of the units – the family-focused care approach; protective paternalistic nature, and differences in end-of-life care planning – can often conflict with the standard 'adult' approach to the donation process. SN-ODs work across all intensive care units; however, applying the donation process to neonatal units requires understanding of the nature of the units and the philosophy they follow. End-of-life care practices differ from adult units and consideration of these is important. For many working in neonatal care, this is a relatively new initiative and processes may not have been fully set up.

Legislation around child death across the UK can prevent donation from occurring, particularly where the cause of death is suspicious or uncertain.[13,16] Working closely with the coroner and police teams in cases of unexpected child death is essential for optimising opportunities in these cases.

Donation from children, especially infants, is a rare event and the specialist and clinical teams may have limited experience in these areas. Targeted training strategies are in place and embedded in NHSBT programmes, which are adapting to meet the needs of the teams attending these cases. The visibility of the specialist teams, and support and training for the clinical teams on the neonatal units is important but SN-OD resources are limited and time is often focused on the adult intensive care units where the potential for donation is greater.

Managing the expectations of families and professionals can be a challenge. Outcomes may be unpredictable and seen as disappointing should the organ go to an adult, fail to be transplanted successfully or if the child does not die in the timeframe required for DCD. The death of a child remains a rare event and donation from children even more so; consequently, exposure for specialist, clinical and retrieval teams is limited. There may be psychological impact for those involved and appropriate and adequate support should be available to mitigate this. Debriefing and training strategies would help.

End of life care is about choices, decisions and the wishes of the family in the time that they have left with their baby. Healthcare professionals work hard to achieve their aims and offer opportunities for families at this difficult time. Organ donation may not be an option that is readily acknowledged, often due to a lack of information about the realistic possibilities. Clinical staff can too easily dismiss the option without clear guidance from specialist teams.

Environment is an important aspect in end of life care provision. Working to ensure the environment is optimal is key to how nursing and clinical staff themselves perceive the death.[17] Organ donation may change this staff perception. For DCD there is need for maintaining a degree of monitoring, withdrawal of treatment in an anaesthetic room and transfer to theatre imminently following death. All of which can cause anxieties within the clinical team without clear explanation and understanding. DBD may bring less anxiety; all support is stopped during the operative procedure and the child can be transferred back to the unit following organ retrieval.

FIGURE 4 NHSBT is developing a national strategy to support donation in paediatric and neonatal areas with the aim of offering families fully supported donation options.

Anecdotally, experiences with parents do not always translate into the anxieties demonstrated by clinical staff. Full and clear explanations are given by the SN-ODs to parents and there are opportunities for the family to express their final wishes. However, there is little research to demonstrate the effects of organ donation on staff and family perceptions in end of life care for children.

National integrated care pathways to support management of donation in hospitals are available[18] and adaptation of these would enable bespoke strategies for children's units to incorporate specific details and expectations and address operational aspects of the process.

Conclusions

NHSBT is committed to supporting the development of donation in paediatric and neonatal areas and a national strategy is currently being developed in line with the overall strategy of *Taking Transplantation to 2020* (**FIGURE 4**). The aim being to ensure that, where possible, families of all infants and children are offered donation options and supported fully in the

process, with the outcome of successful transplantation.

Without bespoke strategies that take into account the specific intricacies of this area of medicine, there is a risk of not providing relevant and meaningful support for the professionals working in this area, nor for the donors and their families.

The call is, therefore, to embrace these challenges: develop bespoke strategies for donation in paediatric and neonatal units; establish accurate data on donor potential; create adequate support and training programmes; share learning and transplant outcome data, and ensure that innovations in transplantation give due consideration to paediatric and neonatal donation.

Acknowledgement

The author is grateful for the contributions of Dr Kay Hawkins of Manchester Children's Hospital, Dr Ajit Mahaveer of St Mary's Hospital, Manchester, and NHSBT Clinical Statistics.

References

1. **Department of Health.** *Organs for Transplants: A Report from the Organ Donation Taskforce*. 2008. Online at: http://webarchive.nationalarchives.gov.uk/20130105051141/http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_082122 [accessed 17 October 2017].
2. **NHSBT.** *Taking Transplantation to 2020*. Online at: www.nhsbt.nhs.uk/to2020 [accessed 17 October 2017].
3. **Brierley J.** Paediatric organ donation in the UK. *Arch Dis Child* 2010;95:83-88.
4. **NHSBT**. Paediatric Care. Online at: www.odt.nhs.uk/deceased-donation/best-practice-guidance/paediatric-care/ [accessed 24 October 2017].
5. **Brierley J., Larcher V.** Organ donation from children: time for legal, ethical and cultural change. *Acta Paediatr* 2011;100:1175-79.
6. **Brierley J.** Neonatal organ donation: has the time come? *Arch Dis Child Fetal Neonatal Ed* 2011;96:F80-83.
7. **Wijetunga I., Ecuyer C., Martinez-Lopez S. et al.** Neonatal organ donation for transplantation in the UK. *Arch Dis Child Fetal Neonatal Edition* 2015;doi: 10.1136/archdischild-2015-308575.
8. **Maluf D.G., Carrico R.J., Rosendale J.D et al.** Optimizing recovery, utilization and transplantation outcomes for kidneys from small, ≤20 kg, pediatric donors. *Am J Transplant* 2013;13:2703-12.
9. **Dave R., Hakeen A., Dawrant M. et al.** Renal transplantation from paediatric donors in the UK. *Transplantation* 2015;99:1968-75.
10. **Dhawan A., Puppi J., Hughes R., Mitry R.** Human hepatocyte transplantation: current experiences and challenges. *Nat Rev Gastroenterol Hepatol* 2010;7:288-98.
11. **RCPCH**. *The Diagnosis of Death by Neurological Criteria in Infants Less Than Two Months Old*. 2015 Online at: www.rcpch.ac.uk/system/files/protected/page/dnc%20guide%20final.pdf [accessed 24 October 2017].
12. **NHS Blood and Transplant.** *Paediatric Donation 1 April 2015 to 31 March 2017*. Online at: https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4663/paediatric_nodc_benchmarking_data_available.pdf [accessed 17 October 2017].
13. **NHSBT.** *Annual Report on Donation and Transplantation in Paediatrics Summary Report for the 12 Month Period 1 April 2016-31 March 2017*. Available from NHSBT on request.
14. **NHS Blood and Transplant.** *Taking Organ Utilisation to 2020*. Online at: www.odt.nhs.uk/odt-structures-and-standards/key-strategies/taking-organ-utilisation-to-2020 [accessed 17 October 2017].
15. **Charles E., Scales A., Brierley J.** The potential for neonatal organ donation in a children's hospital. *Arch Dis Child* 2014; doi: 10.1136/archdischild-2013-304803.
16. **Twamley H., Haigh A., Williment C. et al.** Prospective audit to evaluate the potential of the coronial system to increase solid organ donation. *BMJ Open* 2016;6:e010231.
17. **Beckstrand R., Rawle Callister L., Mandleco B.** Paediatric nurses' perceptions of obstacles and supportive behaviours in end-of-life care. *Am J Crit Care* 2010;19:543-52.
18. **NHSBT**. Procedural Documents. Online at: www.odt.nhs.uk/deceased-donation/best-practice-guidance/procedural-documents [accessed 24 October 2017].

To get involved in neonatal and infant organ donation contact the author Angie Scales (angie.scales@nhsbt.nhs.uk) who can put you in touch with your local SN-OD. For useful resources visit www.odt.nhs.uk.

Want to attend a study day? Check out Paediatric and Neonatal Organ Donation Simulation on 21 May: www.bmsc.co.uk/course/national-paediatric-organ-donation-simulation-course