

Neonatal organ donation – why not?



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The recent news that the NHS has experienced a 50% increase in the number of organ donations over the last five years is very encouraging¹. The success of this is due to a number of factors including an increase in the number of donations following cardiac or circulatory death (DCD – Donation after Circulatory Death). Instead of relying on donation after brainstem death has been confirmed, DCD has increased the pool of organ donors and now this route accounts for one in four kidney transplants. Data from adults show that, on average, recipients achieve an additional 56 years of life from a single donor. There is an increasing demand to consider neonates as organ donors². How many more life years could be gained if neonates were allowed to be organ donors? The neonatal and early infant mortality rates account for more deaths than any other comparable period in childhood. Why is there such inertia in establishing a process for organ donation from neonates?

Since the Academy of Medical Royal Colleges announced that brainstem death testing was not suitable for infants less than two months of age in 1991³, the possibility of neonatal organ donation ceased (at a time when it wasn't even technically possible). For infants less than 37 weeks, the lack of myelination (and delayed brain maturation) and the higher incidence of cardio-respiratory immaturity mean that brainstem death criteria cannot be justified. For infants more than 37 weeks but less than two months of age, the reason why brainstem testing was not recommended was that: "Given the current state of knowledge it is rarely possible to confidently diagnose brainstem death"⁴. Because of this mind-set the prospect of using neonates as donors has essentially frozen ever since.

However a number of neonatal organ transplants have now been successfully performed within the UK for conditions such as hypoplastic left heart. The irony is that the organs are sourced from outside the UK because of the restrictions that we have on neonatal organ donation. Several European countries, Canada, Australia and the USA accept the concept of brain death in the neonate to facilitate donation and do not rely on brainstem death testing.

There has been a successful programme of heart valve donation within the UK for a number of years, which is a testament to the many families who have wanted to help other infants affected by serious medical conditions. Although

it is a very emotive subject with complex ethical and legal issues not fully resolved, there are still a number of infants born with anencephaly each year. Some of these families choose to continue the pregnancy for personal reasons knowing that their baby will die soon after birth. It is a very humbling moment when the families ask if there is any hope that their baby's organs could be used to help others. It is a shame that at the moment, the answer is unequivocally no.

What are the other reasons why practice and research into neonatal organ donation (and transplantation) within the UK is hindered? It could be due to lack of awareness but as neonatal practitioners we should be trying to promote this issue in our everyday practice. Is it due to technical reasons? One of the significant factors in small bowel transplantation is the shortage of suitably sized organs available for infants and young children. Small bowel transplantation is usually carried out for infants older than one year of age but it is technically feasible to perform the procedure earlier. There have also been individual cases of multi-visceral transplants for neonates in North America, which shows there is technical feasibility for organ transplantation even for very small infants⁵. If transplant surgeons within the UK do not operate on younger infants because of lack of experience, the position becomes perpetually self-defeating. Revascularisation of transplanted organs is an important factor but if cardiac transplantation and coronary artery re-implantation can be performed on infants weighing less than 2.5kg, other techniques could be just as successful.

Is it because we lack facilities to harvest organs or to coordinate the process? One of the successes of the adult and paediatric transplant service is the fantastic logistical, psychological and emotional support provided, which could easily extend to the neonatal population. Is it because of a lack of supply? Each year in the UK there are more than 2100 neonatal deaths. With advances in public health, general paediatric and paediatric intensive care, death in childhood is now even less common than ever before⁶. It has been estimated that one in five or six neonates who die could be potentially suitable for organ donation^{7,8}.

The biggest barrier to overcome is to obviate the need for brainstem death testing and accept, as in adult practice, the policy of DCD or brain

death. One of the reasons why this policy has not been adopted is because of 'taboo' or fear, especially in light of the retained organ scandal, that parents would not wish to consider their babies as organ donors. However in practice, I do not think that this will be the case and a number of parents who have agreed to heart valve donation have expressed sadness that other organs could not also be used. There is an irony that, following the Alder Hey retained organs scandal, parents can now request that their own baby's organs be returned to them but they have no right to insist that they be used for transplantation.

There is a new horizon of future therapies. It is now possible to retrieve small bowel, liver and lungs and even possibly cardiac tissue after a period of confirmed circulatory death without significant warm ischaemic injury to these organs. Clearly one of the most significant clinical groups would be infants with severe hypoxic ischaemic encephalopathy (HIE) who have life-sustaining treatments withdrawn. It is precisely because of the profound and irreversible brain injury that palliative care is usually the only option. It would be possible to confirm brain death on clinical, imaging (including magnetic resonance spectroscopy) or electroencephalographic grounds in some of these cases. In others, it would also be possible to consider organ retrieval after DCD.

On the background of such personal tragedy the parents may decide that donation may offer some personal benefit and should surely be explored. The first infant heart transplantation was attempted just three days after the first adult transplantation by Barnard in 1967. Although the outcome was unfavourable, several decades passed before transplantation for hypoplastic left heart became a realistic alternative to staged

repair. Even so, infants under the age of one still have a higher transplant list mortality than any other age group, related to this very small donor pool.

Of course it would be wise to proceed in a very cautious manner – there is very little worldwide experience in this area and long-term outcome data will not be available for some considerable time. Even if a new national policy were to be established, there would continue to be active debate about the ethical and legal dimensions. There should never be any compromise on the respect for human life or disregard for any cultural or spiritual values. Nor should there be any compromise to the provision of high quality intensive care or parental support and to the transition to palliative care, where appropriate. Donation to and transplantation of older children is also still uncommon with less than 40-50 donations per year⁹. Although neonatal death is sadly still common it is unlikely that there will be a substantial donor pool and transplantation itself will be limited to only the most specialised centres.

Recent adult cases have shown how important it is to be certain that death has occurred and a minimum of five minutes should pass after the onset of permanent asystole before death is confirmed. There are a number of complicating factors that must be excluded before a diagnosis of brain death could be considered, including hypothermia, toxicity, metabolic and endocrine conditions. Therefore it would also be vital, before confirmation of brain death in a neonate, that any correctable factors or condition had been considered and reversed. If DCD is to be considered, the precise duration of the timeframe after which death is confirmed is still debateable but perhaps should be 10 minutes rather than five.

The fact that neonatal organ transplantation is permitted with organs

sourced from outside the UK while organ donation is not permitted within the UK, is an ethical paradox. The reality is that the main barrier to neonatal organ donation is not ethical or legal but procedural. Perhaps it is time for the Academy of Medical Royal Colleges to look again at this issue and deliver definitive guidance. There have been many advances in transplantation and for the benefit of neonates and their families, it is perhaps time to look to the future and not in the past.

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