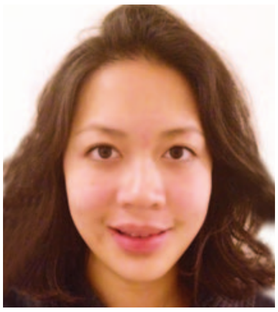
Neonatal organ donation: thinking ahead

Gaurav Atreja
Neonatal Consultant



Faith Zhu
Specialty Trainee in Neonatology

Prathiba Chandershekar
Specialty Trainee in Neonatology

Sunit Godambe
Neonatal Consultant
sunit.godambe@imperial.nhs.uk

Imperial College Healthcare NHS Trust, London

A recent successful neonatal organ donation at a London hospital has been widely reported in the media and generated a lot of interest among the neonatal fraternity.[1] A term female infant with devastating neurological damage secondary to severe antepartum hypoxic insult, who showed no improvement following therapeutic hypothermia, became the youngest organ donor after circulatory determination of death (DCDD) in the UK. Following this event, a recurrent question from media and colleagues has been: "Why is this not happening more frequently?" Unfortunately, in the current scenario in the UK, there is no logical explanation for that. The reality is that the main barrier to neonatal organ donation is not ethical or legal but procedural.[2]

According to guidelines set out in 1991 from the Academy of Medical Royal Colleges for infants less than two months of age: "It is rarely possible to confidently diagnose brainstem death". Even in the absence of guidelines to diagnose brainstem death in infants less than two months of age, DCDD is a feasible alternative,[3] as was demonstrated in our case. Recently, DCDD in the neonatal population has also been endorsed by the UK Donation Ethics Committee.[4] There is hope that new guidelines by the Royal College of Paediatrics and Child Health (RCPCH) working group, which are expected soon, will give clarity in diagnosing brainstem death in neonates and will make the process of neonatal organ donation with the parents simpler.

In children and adults, the favoured pathway to organ donation is after neurological determination of death (DNDD) as compared to DCDD. Even in the neonatal population, the concept of brainstem death diagnosis is not new. The American Academy of Pediatrics updated its guidelines in 2011.[5] According to these guidelines, determination of brain death in neonates relies on a clinical diagnosis that is based on the absence of neurologic function with a known irreversible cause of coma. Two examinations by two independent physicians, including apnoea testing with each examination separated by an observation period of at least 24 hours, are required. Hypotension, hypothermia, and metabolic disturbances must be corrected prior to examination for brain death. During these examinations, the infant should not be under the effect of sedatives, analgesics, neuromuscular blockers and anticonvulsant agents. Ancillary studies (EEG and radionuclide cerebral blood flow) are not required to establish brain death unless the clinical examination or the apnoea test cannot be completed, and are not substitutes for neurologic examination.

For neonatal professionals, the primary motive to offer the parents an opportunity to donate organs from their dying infant should be to give them hope in their most difficult time. In our case, the successful retrieval of both kidneys and hepatocytes followed by transplants into two different recipients, gave the family a positive perspective to the unfortunate tragedy.

There is another very important viewpoint to neonatal organ donation. With an ever improving multidisciplinary approach and advances in neonatal and paediatric care, the need for neonatal organ donors is rising. There are currently 194 young people under the age of 18 waiting for a transplant, of which 15 are babies or infants under two years old. For young children in need of a transplant, the size of the donated organ continues to be a major factor in determining whether they can have the life-saving operation or not. As potential donors of smaller sized organs, this makes neonatal organ donors even more important.[6]

There were a few learning points during this remarkable event. It is not essential for NHS trusts to have expertise in organ donation. Each trust will have a specialist nurse for organ donation (SNOD), who should be the first point of contact. Contrary to popular belief, if one is taking care of an infant at the end of their life, it is appropriate to contact NHS Blood and Transplant (NHSBT) via SNOD even prior to talking to the parents. If it is felt by both stakeholders that there is a potential for organ donation, the clinical team can then discuss this with the parents. If the parents agree for organ donation, NHSBT can then take over the responsibility of formal consent, assessing the suitability of the organs, arranging specialist surgeons and locating suitable recipients, etc. It is important to remember that even after consent is taken, the organ retrieval may not go ahead for various reasons including any compromise in the organ functions, eg renal or liver functions or infection, etc. This should be conveyed to the parents immediately to avoid future disappointment. In our case, the role of the multidisciplinary team was paramount to ensure that the parents were well supported throughout. A clinical psychologist ensured emotional stability of the parents while they made the difficult decision to consent. A senior nurse was allocated exclusively to take care of the baby and the parents. The bereavement process was moulded according to the needs of the parents with careful attention to their background.

Although there has been tremendous improvement in technology combined with improved intensive care, children needing a transplant continue to die due to lack of suitable organs. There are well-established clinical pathways for organ donation in children and adults but not for neonates. There is a pressing need for a consensus to develop pathways for both DNDD and DCDD to be used by neonatal units across the UK. Due to the relative novelty of this aspect of neonatal care, the lack of training and experience in organising and facilitating organ donation is being recognised. There is a need for paediatric and neonatal professionals with experience in this area to develop training and simulation for neonatal organ donation.

References

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