Personal practice

Organ donation

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Transplantation is now an established form of treatment for organ failure in childhood. Much has been published on the outcome and management of children with organ transplants, the ethical issues have been widely discussed, and the criteria for the diagnosis of brain death have been established. Most transplanted organs are taken from donors who are brain dead but have a circulation and are being mechanically ventilated, and recent publicity has drawn attention to a lack of such donors. Staff working on intensive care units, particularly doctors, have been repeatedly criticised for their lukewarm attitude towards organ donation and their failure to ask relatives of patients for permission to remove organs for transplantation. This criticism is primarily directed at those caring for sick adults but the shortage of organs for donation applies equally to children. The current debate is centred on ways of increasing the number of organs donated; by publicity, by obliging staff to ask relatives about organ donation (required request), or by an opting out scheme to replace the present system of organ donor cards. Surprisingly, there is no information to guide doctors caring for a child who is a potential organ donor. It is assumed that organ donation is a straight forward procedure once brain death has been diagnosed and parental consent has been obtained, but this is not so.

An unhappy experience in our own unit recently led to a series of discussions on the subject of organ donation that involved medical and nursing staff and the local transplant team. It became clear that many interests need to be considered, particularly if multiple organ donation is being contemplated: the child and his family, the nurses and doctors responsible for the child's care, the transplant team and its coordinator, the various transplant centres (national and international), the coroner, the pathologist, and the local hospital services such as blood transfusion, theatre, and the mortuary. It was also clear that our unhappiness and unease that had resulted from previous attempts at organ donation arose from divided loyalties and blurring of respon-

sibilities. A series of guidelines were agreed upon and drawn up for future occasions and have since been put into practice successfully. They are presented here in the hope that other paediatricians might find them useful. A few parochial details have been omitted but otherwise the guidelines are applicable to any children's department with intensive care facilities.

The case for transplantation in children

Renal transplantation is now well accepted as the treatment goal for children with end stage renal failure, even for infants less than one year of age. Success rates have continued to improve as experience increases and newer immunosuppressive agents such as cyclosporin are used. Actuarial patient and cadaveric graft survival rates of 98% and 78% respectively at three years post transplant have been reported. Successful transplantation is not only cost effective but the prospects for rehabilitation as measured by school attendance or full time employment are excellent and much better than on dialysis. Unfortunately successful transplantation cannot reverse retarded growth.

There is less experience with liver transplantation but again survival rates continue to improve with a 69% two year patient survival in those less than 15 years of age as reported by the European Transplant Registry. Again the potential for full rehabilitation is considerable and of course there is no other long term support analogous to dialysis in renal failure. Long term follow up after heart and heart lung transplantation in children is limited at present but experience and expertise are increasing and the chances of survival are improving. Corneal transplantation is very successful.

Although it is technically possible to transplant an adult kidney into a child over 2 years of age, an appropriate childhood donor is preferable and this is essential for liver and cardiac transplantation because of the size of these organs.

The obligation of a children's department

Most paediatricians faced with a child in chronic renal failure would refer him or her to a specialist renal unit and they and the parents would expect him to undergo dialysis until a suitable kidney became available for transplantation. Many paediatricians would feel similarly about a young child with chronic liver disease or an adolescent with inoperable congenital heart disease. Current demands for organ transplantation can only be met if donation is considered in every brain dead child who is being ventilated in an intensive care unit. Doctors who are responsible for the care of such children in one of the country's 22 children's intensive care units or in an adult intensive care unit therefore have an obligation to consider organ donation in every case. It is hypocritical to refer children for a transplant but to approach organ donation in a half hearted way.

Which children are suitable donors?

Suitable donors are children who are brain dead, ventilated, and with a stable circulation. Clearly the organs to be donated must be functioning well and therefore particular types of injury or illness may make a child unsuitable as a donor. Major head injury or intracranial illness with relative sparing of the other organs are the commonest situations where organ donation is likely to succeed, but donation is possible if there has been sepsis (for example, meningitis and septicaemia) as long as a period of time has elapsed and the sepsis is clearly controlled. Widespread asphyxial damage will often make organ donation impossible, but if there is evidence that after the asphyxial injury renal function is recovering, with a good urine output and falling creatinine, the kidneys may well be suitable for donation. Children dying from malignant disease will not usually be receiving ventilator support but it is possible that a child with a brain tumour might receive intensive care for an acute complication, perhaps related to surgery. Such a child, if brain dead, would be a suitable organ donor. A child of ours with Reye's syndrome was turned down as a kidney donor. Our rule is always to discuss the possibility of organ donation with the local transplant team rather than dismissing it. We have set a lower age limit of 9 months on the donor as transplantation with organs from the newborn and young infant is uncommon and usually unsuccessful. This may change.

Who should approach the parents, and when?

The most senior doctor who is managing the child's

illness and impending death is the person in the best position to raise the subject of organ donation. This usually means the consultant (paediatrician, paediatric surgeon, neurosurgeon) or the senior registrar attached to our children's intensive care unit together with the nursing sister caring for the child. In other units it might be a consultant anaesthetist. Our own feeling is that the transplant team should not do the asking as they have such a powerful vested interest in the reply. The subject of donation is probably best raised with the parents once it is clear that catastrophic brain damage has occurred and a decision has been made to carry out tests of brain stem death. Increasingly we are finding that parents ask about organ donation before it is mentioned to them. Consent is more likely to be given if the request is made positively rather than as an apologetic gesture, and doctors who have little enthusiasm for organ transplantation should allow someone else to talk to the parents. In cases where there has been an accident the parents should be told that the coroner will require a postmortem examination whether or not organ donation is undertaken. The parents need to give their written consent for organ donation but this is obtained later.

When should the transplant team be approached?

Every hospital where intensive care is carried out has a local transplant team, either at the same hospital or at a nearby centre. The transplant team has a coordinator who is responsible for organising the removal of organs from suitable donors and their transport to a unit (or units) where they will be transplanted. The coordinator may be a permanent appointment to the transplant team or the temporary responsibility of a registrar who is aiming for a career in transplant surgery and engaged in research work. The coordination of organ donation and transplant can be complex and time consuming particularly if multiple organ donation is attempted. The transplant coordinator therefore likes to know in advance that organs may be available. We contact him after the subject has been raised with the parents if they seem to be in favour.

Care of the child before brain death is confirmed

The overriding responsibility of the doctors and nurses on the intensive care unit is to the child and family, not to the transplant team and organ recipients. Medical and nursing staff should not deal with telephone calls from other hospitals asking for details about the potential donor or requesting extra investigations. Such calls and requests should be handled by the transplant coordinator. However, it

is important that careful intensive care of the child continues. Brain death, although likely, is not yet confirmed.

Furthermore if the parents have consented to organ donation, they (as well as the transplant team) will expect the organs to be in a condition that will make successful transplantation likely. Adequate ventilation with monitoring of blood gases must continue and is usually easy to achieve. Infection should be controlled with a broad spectrum antibiotic. Maintaining an adequate blood pressure and effective peripheral perfusion is often difficult in the child with brain stem death because of loss of vascular tone. It is often necessary to give bolus infusions of plasma or saline followed by a maintenance fluid intake that is two to three times greater than normal, and potassium supplements are usually needed. The passage of large quantities of dilute urine is the result of acute diabetes insipidus that follows brain stem death. It will respond to intravenous injections of the vasopressin analogue deamino-D-arginine vasopressin. Occasionally an infusion of an inotropic agent may be necessary.

In our children's intensive care unit this continuing intensive care is carried out by the paediatric medical and nursing staff but some, particularly junior medical staff, may find it unpleasant and distasteful. Those who find it difficult or impossible to give intensive care to a child they know is going to die should not be encouraged to do so.

Support of the family and staff

The hospital chaplains and children's social workers are experts at listening, supporting, and counselling. They play an important part in helping parents through the period of their child's dying and in bereavement counselling afterwards. They also provide invaluable support to the nurses and doctors caring for the child, both at the time and later.

Diagnosis of brain death

We use the clinical criteria for the diagnosis of brain stem death that were drawn up by the Conference of Medical Royal Colleges and Faculties of the United Kingdom.¹⁻³ These are included in a Code of Practice on Cadaveric Organs for Transplantation issued by the Health Departments of Great Britain and Northern Ireland (1983)⁴; the reasoning behind these criteria is powerfully argued by Pallis.⁵ There is no evidence to suggest that brain stem death in infants and children (excluding neonates) is somehow different from adults and the same criteria apply. The tests should not be carried out too soon after the original insult (injury, asphyxia, etc), and

the younger the child, the longer the time that should elapse before the tests are applied, on the grounds that infants are more resistant to brain insults than older children (although there is little evidence to support this). A period of time allows the parents to see that the diagnosis of brain death is made carefully and without hurry, allows them a little time to make the transition from having a healthy child to the child's death, and allows the medical staff to see whether organs considered for donation are functioning. The pace of events must not be influenced by the transplant team.

The tests are performed by two senior doctors: the consultant responsible for the child's care (or his nominated deputy) and another consultant who is unconnected with either the child or the transplant team. The method of performance of each test is clearly described on a form that is inserted in the child's notes and each doctor has to record each test as it is performed. If the exclusion criteria apply (hypothermia, drug induced coma, use of neuromuscular blockers, metabolic disturbances) the tests are postponed. The tests are carried out on two occasions up to 24 hours apart, depending on the time which has passed since the original insult. The parents must know exactly when each doctor is coming to carry out the tests and their performance takes precedence over other duties.

After confirmation of brain death

When the second set of tests have confirmed brain death, the parents are told and written consent is given for organ donation. The parents and family must have an uninterrupted, unhurried opportunity to say goodbye to their child in their own time and way. They will then leave the intensive care unit but some will wish to see the body after the organs have been removed, either back on the unit, in the mortuary, or later at the undertakers. It is extremely difficult for parents to leave a child who may simply look to be asleep, and this is a moment that the nursing staff find particularly upsetting.

Organ removal

The transplant coordinator now takes over all arrangements, fixing up theatres, anaesthetists, blood, transport, etc. He or she may work from a nearby office with a telephone but will not deal with inquiries on the intensive care unit. It may take some hours to make the arrangements if multiple organ donation is being planned but the delay should never be more than 24 hours from the last brain death test and is usually a lot less. The ventilated, brain dead child remains on the intensive

care unit receiving the same medical and nursing intensive care from the same staff. They are better able to maintain the organs in optimal condition for removal than the transplant team.

Certification of death

The child was pronounced dead when the second set of tests confirmed brain death and therefore this date and time should appear on the death certificate.

Consent for a postmortem examination

This has to be obtained separately from consent for organ donation, although it is not required if the coroner requests a postmortem examination. If a postmortem examination is going to be carried out the pathologist should be approached before any organs are removed so that important evidence of a cause of death is not removed at the same time.

Notification of the coroner

Organ donation is not an indication for referring a child's death to the coroner, only the cause or circumstances of the death. If the death is due to trauma, follows surgery, or has occurred under suspicious circumstances, the transplant coordinator would ask the coroner's permission for the removal of organs. Sometimes permission will not be given.

Follow up information

The transplant coordinator will let the staff on the intensive care unit know whether transplant operations took place after organ donation and whether they appear to have been successful. This information is usually given to the donor's parents when they are seen some weeks later for bereavement counselling. It is not appropriate though to give them regular progress reports or to let them know the names and addresses of the recipients, although in some cases this is obvious from reporting in the local or national press.

Discussion

Since we drew up these guidelines we have had the opportunity to put them into practice on about 10 occasions. There is now a positive attitude towards organ donation on the children's intensive care unit. The number of organs donated has increased and most have been successfully transplanted. Nurses and doctors are able to take pride in the fact that they have given every possible care to the child, have managed the parents throughout the child's illness and death, and have helped other children by ensuring that the donated organs were in the best condition for transplantation. Recognition of this and a word of praise from the transplant team is always welcome.

What of the parents? On media discussions about transplantation, parents of children who have died are sometimes heard to say that they wished they had been asked about organ donation. Others say they are glad they had the opportunity to let their child donate organs so that other children might benefit, thus allowing some good to come from their own tragedy. It would be encouraging if this were so but the benefit to parents of organ donation is perhaps too easily emphasised. There is little information about the impact of organ donation on the subsequent process of bereavement in parents and it is not self evident that it has a beneficial effect. This is an area where research is needed.

The authors are grateful to Sister Pippa Waddington and the staff of the children's intensive care unit at University Hospital for their work, support, and professionalism.

References

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