Brain stem death and organ donation—11 years on

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Background. We studied previously patterns of organ donation in a teaching hospital. Eleven years later we repeated the study to investigate how patterns had changed. We also wanted to see whether non-heart beating donation was being practised in our intensive care units.

Methods. All deaths were prospectively audited to identify potential heart beating and non-heart beating organ donors. The actual organ donors and reasons for not donating were identified.

Results. Overall, there was a significant reduction in the number of potential organ donors in the 11-yr period. This was accompanied by an increase in refusal rates by relatives from 10 to 29%, and a decrease in refusal rates by the coroner from 28 to 11%.

Conclusions. In this hospital the number of potential and actual organ donors has fallen in 11 yr. This is a combination of decreasing numbers of patients becoming brain dead and increased relative refusal rate. It has only been partially offset by a more liberal attitude of the coroner and non-heart beating donors.

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In 1989, we published the results of a prospective audit of brainstem death in the intensive care units of Addenbrookes NHS Trust, Cambridge, UK.1 Eleven years later we decided to repeat the audit because of continuing concerns about the shortage of organ donors. In addition, we studied the potential for non-heart beating donors (NHBDs) from our intensive care units.

Methods and results

An almost identical methodology to the previous audit1 was used to identify all deaths and potential organ donors on three of the ICUs in this hospital: the general ICU (JVF ICU), Neurological Critical Unit (NCCU), and Paediatric ICU (PICU). As last time, the neonatal ICU was not included. Ethical approval was considered unnecessary by the Chairman of the Ethics Committee at the time of the study.

In the previous audit, when a patient died a member of the audit team reviewed the notes and completed the audit form. This time the doctor certifying death completed a similar questionnaire that asked about the patient (age, sex, etc.), cause of death, and whether brain stem death was a possible diagnosis. If brain stem death was a possible diagnosis then questions were asked about testing and donation. In addition, a nominated person (either nursing or unit administrative staff) on each intensive care unit identified all deaths, and checked that the audit form had been completed. This was then collected and sent to the audit department for inputting into the database. To ensure all deaths had been recorded, the audit department ran a monthly report from the Hospital Information System to capture the data and location of all deaths and checked those occurring in the ICUs against completed forms.

Organ donation was excluded if the patient had major systemic sepsis, a history of malignancy (except some
primary brain tumours), or infection with a transmissible fatal infection for which there is no known cure.²

Potential NHBDs were defined as patients in whom death was imminent and treatment was no longer of benefit to them, aged less than 60 yr and with no contraindication to organ retrieval (such as HIV infection). If cardiac arrest had occurred then no period longer than 30 min without cardiopulmonary resuscitation should have been suffered. These criteria were based on those developed in Leicester.³

In total, there were 1482 admissions and 186 deaths in the three units within this hospital during the audit period (November 2, 1998 to November 1, 1999). Complete data were obtained in 181 (97%) of deaths. There were 630 admissions and 107 deaths in the JVF ICU, 437 and 59 in the neurosurgical ICU and 417 and 15 in the paediatric ICU. There were one, four, and zero patients who went on to donate, respectively. This information is summarized and compared with the earlier study in Figure 1.

Fig 1 Organ donation for 1 yr in a teaching hospital. Numbers in italics in the box `Potential BSD organ donors’ are the numbers from 11 yr ago. NHBD, non-heart beating donor; BSD, brain stem dead; TC, transplant co-ordinator.
Comment
Since the previous audit in 1988, the shortage of organ donors has continued and the gap between the number of donors and recipients has increased. In 1988 there were a total of 869 donors and 3684 potential recipients while in 1998, there were 846 and 5806, respectively, in the UK (UK Transplant—Annual Reports).

The biggest difference in the current study from the previous one was the reduction in potential organ donors from 52 to 14. There are probably several reasons for this, including significant improvements in road safety, and improvements in the management of subarachnoid haemorrhage and road traffic accidents developed at this hospital.

In all UK studies, refusal by the relatives is the commonest cause of failure to obtain organs, usually in the region of 30% of all potential donors. In our first audit, we had a very low refusal rate of 10% (5/52), and in this one it had increased to 29% (4/14), the national average. The reason for this increase is unknown.

Relatives are usually asked if they know the potential donor’s wishes. Often this has not been discussed and reliance is placed on the family doing what they think the potential donor would have wanted. An organ donor card may have been completed, but is often unavailable. To overcome these difficulties the NHS Organ Donor Register was started in 1994, allowing people to register their wish on a central computer. The effect of the Register was started in 1994, allowing people to register their wishes on a central computer. The effect of the Register on the number of donors has not been determined. Recent changes, and making it available not just to transplant coordinators, but also to ICU doctors and nurses may allow the potential donor’s wish to be more readily known at the start of a discussion about organ donation.

In 1998, there were no instances of relatives not being asked, unlike the earlier study when three were not asked. There was also a marked decrease in the number of donors where the coroner objected to removal of organs. Coroners have wide ranging discretion in their powers; this leads to large differences in practice between individuals, as this study shows. When we asked English coroners about theoretical cases that may or may not need referral to them, we found differences of up to 40% in whom they wanted to be referred to them (unpublished observation).

One option to increase the number of organ donors is the use of NHBDs. They can be used to obtain livers, pancreas and long bones as well as kidneys from patients in the ICU. Organ retrieval from NHBDs in the ICU is more predictable than in the accident and emergency department, making it easier. It was disappointing that organ donation in NHBDs was only considered in six of the 12 potential donors. The reason for this is unclear and may represent unfamiliarity with the process. Since this audit, organ donation from NHBDs has increased, probably because of greater familiarity with the process. Since the numbers of potential donors seems to be decreasing this makes all donors increasingly precious, be they heart-beating or cadaveric donors. Even relatively small numbers will make a difference.

Until alternatives to solid organ transplantation can be found, other options need to be explored. More effective use of existing organ donors and the use of NHBDs are options that can be explored. Changing the public’s perception of organ donation to reduce the refusal rate, in combination with better use of the Organ Donor Register may have a greater effect.

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