

in terms of time, as we assumed that quantification of their delay by patients would be too inaccurate. Additionally, defining a level of “acceptable delay” makes no sense from a medical point of view.

The Geneva Convention of 1949 and the additional protocols of 1977 mandate the right to access to medical care for civilians under occupation. The reported delay in access to healthcare facilities is not in accordance with these principles.

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Potential for organ donation in the United Kingdom: audit of intensive care records

Kerri Barber, Sue Falvey, Claire Hamilton, Dave Collett, Chris Rudge

UK Transplant,
NHS Blood and
Transplant, Bristol
BS34 8RR
Kerri Barber
principal statistician
Sue Falvey
*director of donor care
and coordination*
Claire Hamilton
senior statistician
Dave Collett
*director of statistics
and audit*
Chris Rudge
*managing and
transplant director*

Correspondence to:
C Rudge
chris.rudge@uktransplant.nhs.uk

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Abstract

Objectives To determine the true potential for solid organ donation from deceased heartbeating donors and the reasons for non-donation from potential donors.

Design An audit of all deaths in intensive care units, 1 April 2003 to 31 March 2005. The study was hierarchic, in that information was sought on whether or not brain stem testing was carried out; if so, whether or not organ donation was considered; if so whether or not the next of kin were approached; if so, whether or not consent was given; if so, whether or not organ donation took place.

Setting 341 intensive care units in 284 hospitals in the United Kingdom.

Participants 46 801 dead patients, leading to 2740 potential heartbeating solid organ donors and 1244 actual donors.

Main outcome measures Proportion of potential deceased heartbeating donors considered for organ donation, proportion of families who denied consent, and proportion of potential donors who became organ donors.

Results Over the two years of the study, 41% of the families of potential donors denied consent. The refusal rate for families of potential donors from ethnic minorities was twice that for white potential donors, but the age and sex of the potential donor did not affect the refusal rate. In 15% of families of potential donors there was no record of the next of kin being approached for permission for organ donation.

Conclusions Intensive care units are extremely good in considering possible organ donation from suitable patients. The biggest obstacle to improving the organ donation rate is the high proportion of relatives who deny consent.

Introduction

The United Kingdom has a serious shortage of organs for transplantation, as does almost every country. The

number of deceased heartbeating donors has remained relatively static since 1998, ranging from 644 to 739 donors a year, having fallen from a peak of 923 in 1989.^{1 2} The heartbeating donor rate in 2004 was 12.3 per million population, which is one of the lowest rates in western Europe. Spain has an exceptional rate of 33.0 per million population, but most other countries in Europe have rates between 13 and 22 per million population (see bmj.com).³

Only one systematic study has been performed of the potential for organ donation from intensive care units, which was carried out in 1989-90 and was restricted to England and Wales.^{4 5} This estimated that in 1200-1350 patients a year death was diagnosed after brain stem tests and that half of these patients became actual organ donors. It also reported that, when approached, 30% of relatives of potential donors refused consent for organ donation, though differences in methods prevent direct comparisons with our study.

UK Transplant was established in 2000 with a specific responsibility to introduce measures to increase organ donation. As part of this process a national potential donor audit was developed to identify the true potential for organ donation from dead donors, together with the reasons for non-donation. We describe the establishment and implementation of the potential donor audit together with the overall results from the first two years for potential heartbeating donors.

Methods

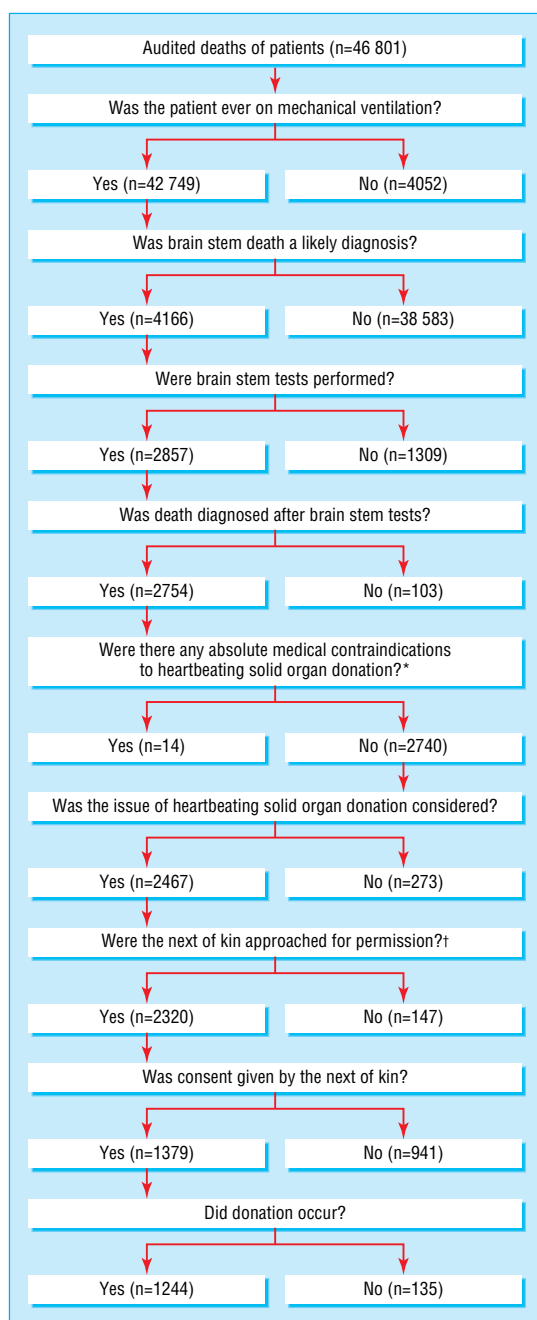
The potential donor audit was designed on a hierarchical basis. Basic demographic information (not



The audit form is on bmj.com.



This is the abridged version of an article that was posted on bmj.com on 26 April 2006: <http://bmj.com/cgi/doi/10.1136/bmj.38804.658183.55>



A breakdown of the 46 801 audited deaths (*either known or suspected variant Creutzfeldt-Jakob disease or known HIV infection; †includes cases where the next of kin made the approach)

patient identifiable) is obtained for all patients who die in an intensive care unit, together with date, time, and cause of death. This is followed by questions concerning whether or not death was diagnosed by brain stem testing, whether or not solid organ donation was considered, the process by which relatives were approached, and whether or not consent was obtained. Finally, information is requested on whether or not organs were offered for transplantation and whether or not organ donation occurred.

The final version of the audit form is on bmj.com. Data are collected by donor transplant coordinators, donor liaison nurses, and some intensive care unit link nurses. All forms are submitted to UK Transplant for

data entry and validation checks. Strenuous efforts are made to ensure that the study includes all intensive care units in the UK with the potential for providing deceased heartbeating solid organ donors and that forms for all deaths are completed.

Fully validated data on deaths in intensive care units are available from 1 April 2003. In the first two years of the audit, up to March 2005, data were obtained on 46 801 deaths in 341 intensive care units in 284 different hospitals.

Results

The figure shows a schematic breakdown of the 46 801 audited deaths. Around 41% of families denied consent (95% confidence interval 38.6% to 42.6%). We refer to this as the refusal rate.

The table shows the main reasons given for relatives' lack of consent. Individuals may have given more than one reason. No single reason was given much more commonly than any other. Other reasons for refusal were given by 244 families (26%) and included "the family wanted to be with the patient when the ventilator was turned off," "religious beliefs," and "the family do not agree with organ donation."

The refusal rates for males and females and the six age groups did not differ significantly. There is strong evidence of a difference in white and non-white potential donors based on the 2174 potential heartbeating donors whose ethnicity was recorded, the refusal rate for whites being 35% (33% to 37%), while that for the group of ethnic minorities is 70% (63% to 77%) (see bmj.com).

Discussion

The national potential donor audit is the first comprehensive, UK-wide study to try to identify the number of patients dying in intensive care units who could donate their organs for transplantation. Data have been collected within two to four weeks of each death. This does not seem to have resulted in missing data, a tribute to those collecting the data.

Potential for organ donation

The starting point for heartbeating organ donation is the number of patients whose death is confirmed by brain stem testing and in whom there are no absolute contraindications to organ donation. In the two year period analysed, the maximum number of potential heartbeating organ donors was 2740. This equates to a maximum achievable rate of potential heartbeating donors of 23.2 per million population per year. This maximum potential rate is well below the actual donor rate achieved in Spain. The potential donor audit

Reasons given by relatives for denying consent to solid organ donation

Reason	Proportion*
Patient stated in the past he/she did not want to be a donor	16
Relatives not sure whether patient would have agreed to donation	19
Relatives divided over decision	16
Relatives thought patient had suffered enough	16
Relatives did not want surgery to body	20
Reason not documented	17

*Of 941 who refused.

shows that while in 4166 patients the diagnosis of death by brain stem testing was possible, only 2857 patients underwent formal testing. The outcome of the 1309 remaining patients is not known, but a proportion of these patients could have become potential heartbeating donors had brain stem death been tested for. They may have been suitable non-heartbeating donors, and the potential donor audit has recently been extended to provide data on such patients.

Approach and refusal rate

After the diagnosis of death by brain stem testing, in 273 patients there was no record that organ donation was considered and in 147 no record that relatives were approached for consent. This amounts to 15% of potential donors. Further data are needed to clarify whether lack of documentation equates to lack of consideration or approach.

Of the relatives of 2320 potential heartbeating donors who were approached for consent for donation, 41% refused consent during the two years of this study. When the Human Tissue Act 2004 comes into force in September 2006, the legal position will be that the wishes and consent of the individual will be paramount. It is therefore important that individuals ensure that their families are aware of their wishes in regard to organ donation. If a patient carries a signed donor card or has registered their wishes on the organ donor register, there is no legal requirement to establish lack of objection on the part of the relatives. In practice, however, if a relative denies consent, organ donation might not proceed.

Conversion rate

Differences in rates of organ donation in different areas of the UK⁶ and between countries³ are often expressed as differences in the donor rate per million population. This measure, however, is influenced by several factors including the provision of intensive care beds, neurosurgical practice, and the death rates from intracerebral bleeding and road traffic accidents. It is far more realistic to consider the donor rate in terms of a "percentage of the potential" or the "conversion rate."⁷⁻⁹ In the United States, a retrospective review of records in a sample of the organ procurement organisations,⁸ found that the refusal rate for consent for organ donation was 46% and that the conversion rate (the number of actual donors divided by the number of potential donors) was 42%—a figure similar to ours (45%). A conversion rate of 100% cannot be surpassed and therefore represents total success, whether that translates into five donors per million population or 50 donors per million population.

The UK potential donor audit seems to be the only national, ongoing study of its type in the world. More detailed analyses of the data are being done. It is clear, however, that the single biggest obstacle to improved rates of organ donation from heartbeating donors is the number of relatives who refuse consent. The new legislation that comes into force in September 2006 may, in time, address this aspect and emphasises the benefits that can follow increased registrations on the NHS organ donor register.

We are grateful to all those who have contributed to this study, particularly the donor transplant coordinators and their

What is already known on this topic

In the early 1990s, the refusal rate for organ transplantation in England and Wales was 30%

What this study adds

From April 2003 to March 2005, 41% of relatives of potential donors in the UK declined to give consent for heartbeating solid organ donation

Families of 94% of patients who could have been solid organ donors were approached, or initiated an approach, for consent to donation

The maximum achievable potential donor rate during this study period was 23.2 per million population per year, well below the actual donor rate achieved in Spain

regional managers, the intensive care societies, and critical care networks.

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Endpiece

A textbook type of mind

I think it is a fact that the students of the "text-book type of mind" and who have very good verbal memories, are lacking in "clinical instinct" and do not turn out such good doctors as others who shine less at examinations.

Sir Robert Hutchison. *Common sense in medicine*. *London Hospital Gazette* 1942;XLV:36.

J G Fairer, St Jean d'Angely, France