

Demographic factors influencing consent for cadaver organ donation

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Summary

The records of all donor referrals to Groote Schuur Hospital over a 5½-year period were retrospectively examined to determine which factors influenced the families' decision on organ donation. In 35% of these referrals the families were not approached for consent. The reasons for this included the potential donor being unsuitable for organ donation or not meeting all the criteria for brain death. The effects of the age, sex, race and the cause of death of the potential donor on whether the family gave consent were investigated. This study demonstrates that consent was given more readily when the potential donor was aged ≤ 10 years, that the sex of the potential donor appeared to have no effect on the decision by the family about organ donation, that black families gave consent for organ donation less frequently than families of other race groups and that consent was obtained more easily when death was due to suicide.

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The shortage of cadaver organ donors is a major problem in solid organ transplantation.^{1,2} The reasons for this include failure to recognise potential donors combined with an apathy among the medical profession about referring brain-dead patients as potential donors.³ If all potential donors were referred by the medical profession, the number of refusals by the public would be so few as to constitute no significant problem. There also appears to be an unwillingness among certain groups to donate organs (personal experience). To

date, no comprehensive surveys have been conducted that examine this issue.

Two basic types of organ procurement legislation exist world-wide today — presumed consent ('opt-out') and required consent ('opt-in').⁴ The policy of presumed consent, which has been adopted by most European countries,⁴ allows for the removal of organs from a cadaver without consent from the family unless the deceased has indicated before his/her death that he/she has an objection to organ donation. South Africa, like the rest of the English-speaking world,⁴ has a policy of required consent where consent is either requested from the next-of-kin or it is indicated by the donor before death (donor cards/ MedAlert discs).⁵ For a policy of required consent to be effective, an informed, altruistic public⁴ and a motivated medical profession are required. Many potentially transplantable organs are lost because consent for organ donation cannot be obtained from the next-of-kin.

In an attempt to determine whether there were any factors that influenced families to give consent for organ donation, the records of all donor referrals over a 5½-year period were retrospectively examined. By highlighting these factors we hoped to identify those groups of donor families, if any, which needed to be approached for consent in any special way.

Subjects and methods

This retrospective study examined the records of all cadaver donor referrals to the renal and cardiac transplant units at Groote Schuur Hospital between 1 January 1984 and 30 June 1989.

Referral procedure

Potential organ donors were identified and certified brain dead (irreversible loss of all brain function) by the doctor in charge of the patient. The standard criteria for the diagnosis of brainstem death⁶ were used. Once certified brain dead, the

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patient was immediately referred to the transplant co-ordinators attached to the renal and cardiac transplant units.

The post of transplant co-ordinator was created at Grootte Schuur Hospital in 1981 and was filled by a registered nurse with psychiatric and/or intensive-care experience. In 1987 a second transplant co-ordinator post was created. The transplant co-ordinators offer a 24-hour service for donor referrals. It is the duty of the transplant co-ordinator to make the initial assessment of the potential donor, to take over further management of donors inside the Cape Town metropolitan area, as well as to approach the family about consent for organ donation.

When the donor referral is from outside the Cape Town metropolitan area (12% of cases) the family is approached for consent by the doctor in charge of the patient. If the potential donor is in possession of a donor card or MedicAlert disc indicating the desire to be an organ donor (3 cases) the family is still approached for consent. The knowledge that the person had already indicated a wish to be an organ donor made the decision very much easier for the family.

In cases where the patient is either unidentified or where there is either no family or where the family cannot be contacted, consent is obtained from the district surgeon according to the criteria laid down in Section 2 (26) of Tissue Act No. 65 of 1983.⁵

Data collection

Each donor referral is documented and data including the age, sex, race, cause of death and whether consent was given are recorded by the transplant co-ordinator. Initially these details were entered into a 'Donor Referral Book' and later (1 January 1987) onto a specially designed donor referral form. These data are entered by the transplant co-ordinator into an IBM-compatible microcomputer database (Paradox 2.0, Ansa Software) for analysis.

Statistical analysis. Data were statistically analysed using χ^2 analysis (for 2×2 tables) and Fisher's exact test (for 2×2 tables where any cell number was less than 5). A *P* value of $< 0,05$ was regarded as statistically significant. The statistical analyses were performed using a microcomputer program, Epistat.

Results

Donor profile

During the study period 566 potential organ donors were referred to the transplant co-ordinators (424 males and 137 females; the sex of the donor was not recorded in 5 cases). The mean age was 28 years (range 1 day - 86 years). The 1-day-old donor was an anencephalic child. The age of the donor was not recorded in 32 cases. Of the potential donors, 150 were white, 296 were of mixed race and 111 were black. The race of the donor was not recorded in 9 cases.

Cause of death

The causes of death in the 566 potential donors are shown in Fig. 1. Death was due to trauma in 372 donors (65,7%). Eighteen per cent of deaths were due to medical causes. Suicide, mainly due to gunshot wounds to the head, was the cause of death in 38 of the donor referrals (6,7%).

Families not approached for consent

In 198 of the donor referrals (35%), the family was not approached for consent; the reasons are shown in Fig. 2.

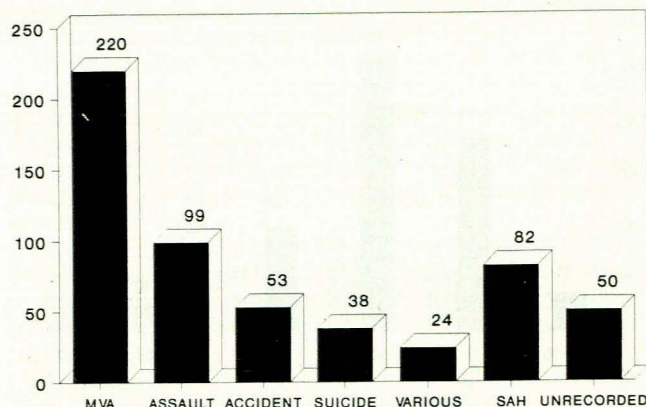


Fig. 1. The causes of death in the 566 donor referrals.

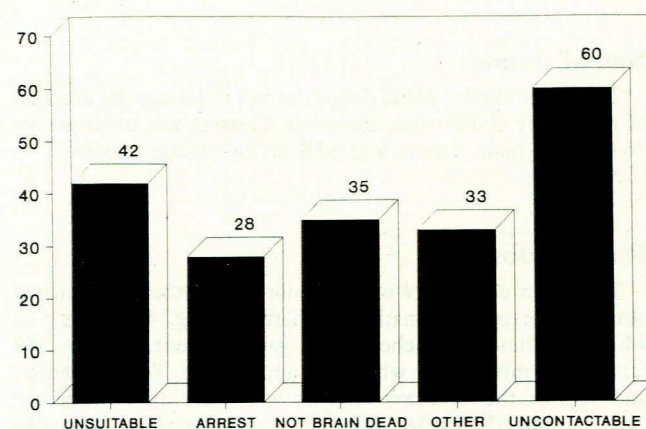


Fig. 2. Reasons why the families of 198 potential donors were not approached for consent for organ donation.

Twenty-one per cent of the potential donors were unsuitable because of prolonged hypotension and anuria or because there was underlying malignant disease, a history of diabetes or a history of severe hypertension. In 5% of cases the potential donor had a cardiac arrest and could not be resuscitated, and 6% of potential donors did not meet all the criteria for brain death and therefore could not be considered for organ donation. Seventeen per cent were not considered for a variety of reasons, including HBsAg and HIV-I positivity (because of the obvious risk of infection for the recipient and the transplant surgeons and staff), religion (in our experience Muslim and Jewish families seldom give consent for organ donation), and age (the age limits for donors at our institution are under 8 years and over 60 years).

Consent

Of the 566 donor referrals, 368 families were approached for consent and 78% gave permission for the removal of organs.

Age of donor

The effect of the age of the donor on consent for organ donation is shown in Fig. 3. Families of donors aged ≤ 10 years gave consent more frequently than those in all other age groups ($P = 0,02$; Fisher's exact test). In this group consent was obtained in all 15 cases. The largest group of donors were those between the ages of 21 years and 30 years. In this group consent was obtained in 78,5% of cases.

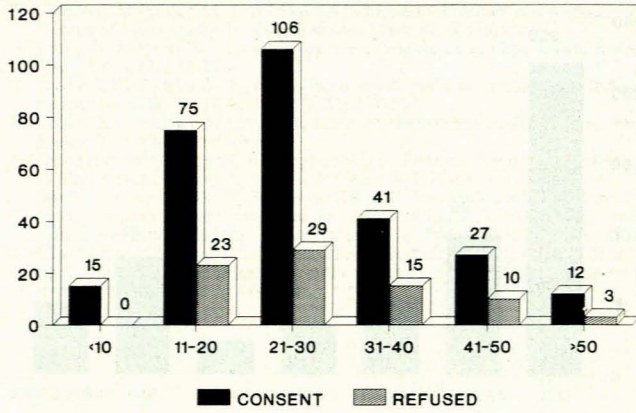


Fig. 3. The effect of the age of the potential donor on consent for organ donation (age was unrecorded in 10 cases).

Sex of donor

The sex of the potential donor did not influence the decision of the family about organ donation. Consent was obtained for 76% of the male donors and 82% of the female donors ($P = 0,29$; χ^2 test).

Race of donor

The effect of the race of the donor on whether consent was obtained for organ donation is shown in Fig. 4. Of the 127 white families approached, 91% gave consent. Of the 189 families of mixed race who were approached, 74% consented and 42% of the 50 black families who were approached for consent agreed. These differences in consenting to organ donation were statistically significant when all the race groups were compared ($P = 0,00002$; χ^2 test). When consent from black families was compared with consent from both white and mixed families the differences remained statistically significant ($P = 0,0004$; χ^2 test).

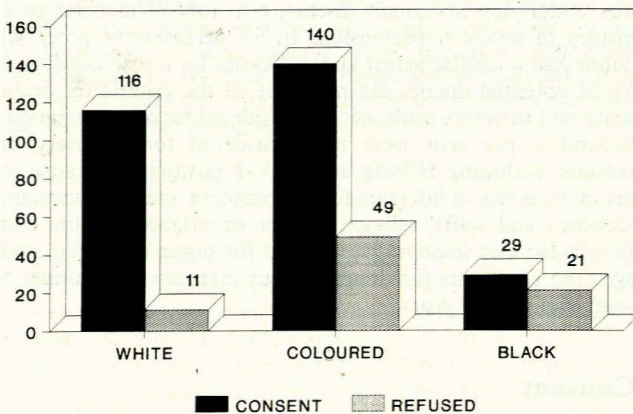


Fig. 4. The effect of the race of the potential donor on whether consent was obtained for organ donation (race was unrecorded in 2 cases).

Cause of death

The effect of the cause of death of the donor on the number of donor families who gave consent for organ donation is shown in Fig. 5. There was no difference in the frequency of consent for organ donation between these groups. Consent was obtained in 75% of the 236 patients where death was related to

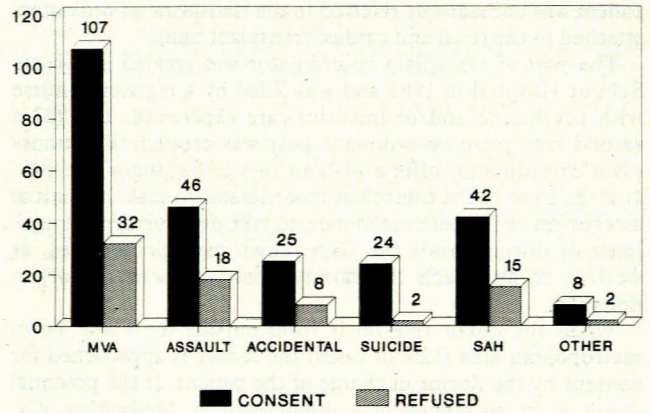


Fig. 5. The effect of the cause of death of the potential donor on whether consent was obtained for organ donation. The cause of death was unrecorded in 39 cases (MVA = motor vehicle accident; SAH = subarachnoid haemorrhage).

trauma due to MVA, assaults and other accidental causes. Similarly, consent was obtained in 75% of the patients who died of medical causes, such as subarachnoid haemorrhage, cerebrovascular accidents and hypoxic brain damage following respiratory arrest. Consent was obtained from the relatives in 92% of the 26 patients whose death was due to suicide. When consent from this group of donor families (suicides) was compared with the rest of the donor families a significant difference was found ($P = 0,03$; Fisher's exact test).

Unknown/unidentified potential donors

In 11% of the donor referrals the potential donor was either unidentified, had no family or the family could not be contacted. In recent years the option of obtaining consent for organ donation from the district surgeon in these cases has been used increasingly. This is legally acceptable provided all reasonable steps have been taken to trace the family and the transplant is considered necessary to save the life of a patient.⁵ Consent was obtained from a district surgeon in 43% of the 60 potential donors who were either unidentified or whose family could not be traced.

Discussion

The lack of cadaver organs continues to be a major limiting factor in solid organ transplantation.^{1,2} The apathy among the medical profession about referring brain-dead patients as potential donors³ to the various transplant centres may be related to a fear of the legal implications of the certification of brain death and organ donation, an unwillingness to approach the grieving family for consent, and also ignorance about the success of transplantation.² The aim of this study was to investigate the factors that might influence the decision of the family about organ donation and in this way attempt to highlight problem areas in obtaining consent.

Consent was given more readily when the donor was aged ≤ 10 years. The reason for this is unclear. Bartucci and Seller⁷ report that one of the most common reasons why families donate cadaver organs is to try to make 'something good come from a tragedy'. Most families find comfort in the knowledge that by donating the organs of a loved one they are able to get something positive out of the situation — they are able to turn a personal and family tragedy into a tremendous gift for others, the gift of life.⁷ A Canadian report on public attitudes toward organ donation⁸ states that most people felt very

positive about donating the organs of a minor child. Families appear to take comfort in the knowledge that they are able to help another child;⁸ they may also try to immortalise the child in the body of another,^{8,9} and in this way put off having to face the death.⁹

The sex of the donor had no effect on which families gave consent for organ donation. There were three times more male than female subjects referred as potential organ donors.

Obtaining consent for organ donation from black families is difficult, although the number of black families who consent has increased steadily over the past few years. A refusal rate of 58% in the South African black population compared with figures reported by Perez *et al.*¹⁰ in America, where 45% of American black families in New York City, Los Angeles and Miami refused consent for organ donation. The refusal rate among white families in the same population was 17%,¹⁰ which is higher than that reported in this study (9%).

As yet, no survey has been carried out in South Africa to determine the attitudes of black people to organ donation, although one is soon to be commissioned by the Organ Donor Foundation of South Africa. Callender¹¹ found that the major reasons why black Americans refused to give consent for organ donation were lack of knowledge, religious fears, fear of complications and lack of communication between lay families and health care workers. These factors are possibly also true of the black people of South Africa. The solution would appear to lie in the education of the black population about organ donation and transplantation. This would allay many of the anxieties and suspicions that surround the issue. The fact that more and more black patients are having transplants and returning to the community may help to increase awareness about transplantation and the need for organ donors. The appointment of a black transplant co-ordinator may also help to improve communication.

The cause of the death of the donor appeared not to influence which families gave consent, except where the donor committed suicide. In these cases consent appears to be given more readily. This might be seen as a last noble act by the family to give meaning to an otherwise disappointing life.⁹

Every effort should be made to contact the family of potential organ donors for consent, but if this fails then consent for

organ donation should be obtained from a district surgeon. In this way many transplantable organs will be saved.

This study has demonstrated that the sex of the donor appears to have no effect on the decision by the family about organ donation. Consent was given more readily when the donor was aged ≤ 10 years. Black families gave consent for organ donation less frequently than families of other race groups. Consent was obtained more easily when death was due to suicide.

The families of all potential donors must be treated with the utmost respect and consideration, whether they give consent to organ donation or not. Through education and by gaining the support of the public the supply of cadaver donor organs must increase.

Much pain could be averted if every family discussed the issue of organ donation now, so that when faced with the decision of whether or not to give consent, there is no turmoil and the family is able to carry out the wishes of the deceased.

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