

Attitudes to organ donation among South Asians in an English high street

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SUMMARY

In the UK, people of South Asian origin are at more than twice the risk of end-stage renal failure encountered in the Caucasian population but are under-represented among organ donors. Difficulties with matching mean that few donated kidneys are suitable for transplantation to South Asian recipients. A survey of attitudes in 100 South Asian adults was conducted in the main street of Southall, Middlesex. 90 of those questioned were aware of organ transplantation and 69 had heard about donor cards. However, the 16% who carried a donor card was lower than the 28% reported in the general population. The main reason for the low organ donation rate by South Asians seemed to be lack of knowledge, and this could be remedied by more targeting of information in the Asian media.

INTRODUCTION

The national shortage of kidneys donated for transplantation in the UK is of particular concern to people from the Indian subcontinent (South Asians). They already wait longer than Caucasians for suitable kidneys and the imbalance is likely to become worse. First, there is a shortage of South Asian organ donors: 95% of the organ donor pool is of Caucasian origin whereas 20% of the patients waiting for a transplant are from the ethnic minorities¹. This immediately disadvantages South Asians in terms of histocompatibility and ABO blood group matching. Differences in blood grouping are the most important factor. The B blood group allele is most common in South Asians whereas the O and A alleles predominate in Caucasians; thus, few donated kidneys are suitable for transplantation to Asian recipients. Matters are unlikely to improve unless more South Asians can be recruited onto the organ donor register or some other source of kidneys is found.

Secondly, it seems, although more research needs to be done, that the proportion of South Asians admitted to intensive therapy units is much lower than that of the native population, so that the opportunities for obtaining their organs in this setting will be fewer².

Thirdly, South Asians are two to three times more likely than Caucasians to go into end-stage renal failure (ESRF)³, a difference that rises with age to seven times in those over 55 years. The explanation lies in their much higher incidence of diabetes mellitus⁴, diabetic nephropathy being the biggest single cause of ESRF in this ethnic group. This

has an important bearing since more elderly people are now being accepted for renal replacement therapy (dialysis and transplantation). At present more than one-third of patients awaiting kidney transplants in the North West Thames region are of South Asian origin. Similar figures are reported for other regions with large South Asian populations and they are set to rise. We conducted a street survey of attitudes to organ donation in this population group.

METHODS

A structured questionnaire was devised and the interviews were conducted in the main thoroughfare of Southall, Middlesex, where the population is predominantly South Asian. The interviews were conducted at different times on different days and with South Asian men and women over the age of 16 years. Care was taken to ensure a range of ages and different ethnic and religious backgrounds. Since many older South Asians, especially women, do not speak English, some interviews were conducted in Hindu, Urdu or Punjabi. Names and addresses were not recorded.

RESULTS

50 men and 50 women, between the ages of 16 and 74 years, were interviewed; 38 were Sikh, 25 Hindu, 38 Muslim and 1 agnostic. 90% of the people interviewed were aware that organ transplants are possible. Knowledge about kidney and heart transplants (99 and 86) was more widespread than that about liver and lung transplants (72 and 52). 40 of those questioned knew of someone on renal dialysis (relative, friend, acquaintance).

Although 69 of the 100 had heard of the organ donor card, only 16 carried one. Of these 16 card carriers, 11

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were women and 11 knew someone who had had an organ transplant or was on renal dialysis; 10 of these had been educated in the UK. The reasons given for not carrying an organ donor card were 'never heard of it' (33), unsure from religious standpoint (7), personal feelings (26) and other (33).

Of the 7 people who were not sure whether their religion allowed organ donation and transplantation, 6 were Muslim. 'Other' reasons included 'not really thought about it' or 'not bothered doing it'. When asked whether they would consider donating one of their kidneys if a close relative had kidney failure, 48% of non-card-carriers said yes. Suggestions for encouraging the carrying of donor cards included: more information in the Asian media (32%); more information in Asian languages (26%); religious approval (13%); encouragement by community leaders (3%) and other ways, such as provision of literature at community and religious centres (26%). Lack of information about transplantation, fear and religious uncertainty were the main reasons for the reluctance of Asians to come forward as organ donors. More than 60% of the people questioned thought that these attitudes could be changed by providing more information through Asian television, radio and press.

DISCUSSION

There have been very few published studies of attitudes to organ donation and transplantation in the general South Asian population. Here we aimed to canvas opinions from all the groups that represent the Indian subcontinent in Britain, in the sample of 100 interviewees.

The finding that 90% of South Asians were aware that organ transplants are possible, with almost universal knowledge of kidney transplantation, is an important basis on which to increase knowledge about organ donation. A staggering 40% of the people interviewed knew someone on renal dialysis. This indicates the very high prevalence of renal failure in Asians in this area and shows that community networks are important in disseminating knowledge about renal disease. Patient groups might therefore have an important role in raising awareness.

Only 69% of the sample had heard of the organ donor card, compared with a 97% figure obtained for the general population by three independent surveys in 1992. The 16% carrying the donor card is also well short of the 28% reported for the general population⁵. 11 of the 16 card carriers were women and most of these knew someone who had had an organ transplant or was on renal dialysis. This may indicate that women are more sympathetic to organ donation.

The fact that 10 of the card carriers had been educated primarily in the UK may reflect their better position to pick

up information from the general press. It is noteworthy that 48% of non-card-carriers said they would offer one of their kidneys if a close relative had kidney failure. In this population, therefore, live related donation may be a more effective way of countering the organ shortfall than cadaveric donations—although the high prevalence of diabetes mellitus, hypertension and obesity in this group might disqualify many would-be donors⁶.

Although religion is sometimes perceived as an obstacle to organ donation by South Asians only 7 of the 100 were doubtful whether their religion allowed transplantation. 6 of these were Muslim, and for this religious group the position could be clarified by publicizing the Muslim Law Council's fatwah (religious edict) permitting organ donation and transplantation⁷.

How should the donor card be promoted further in the South Asian community? More information in the various languages was suggested, yet the Department of Health has already issued material in all the major languages of the subcontinent. Most people interviewed were unaware of this and suggested that literature should be made available in community centres and places of worship as well as general practice surgeries. Another proposal was that Asian television and radio networks might help to educate the community by discussing issues surrounding organ donation and transplantation. This strategy was adopted by the Department of Health in its South Asia campaign, launched in February 1999. The impact of this campaign, on Asian attitudes to organ donation remains to be seen.

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