Awareness of organ donation in the South Asian community

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The South Asian community in the UK is the most under-represented population among organ donors.[1] The South Asian community makes up a mere 1–2% of the donors on the NHS organ donor register, despite the fact that this population group is more likely to require certain transplants.[2] For example, South Asians are three times more likely than the general population to require kidney transplants, due to their increased susceptibility to chronic conditions such as hypertension and diabetic nephropathy.[3]

Although almost all ethnic minority groups are less likely to consent to donation of organs from relatives or themselves compared with caucasians,[4] the figures are particularly low in the South Asian community. This is despite the fact that up to 1,200 South Asian patients[1] are currently on the transplant waiting list, with 20% of patients requiring a kidney transplant[5] from a South Asian background – and these figures are even higher across many areas in the UK.[6]

Reasons for South Asians being severely under-represented on the organ donor register include a lack of awareness of an organised organ donation scheme, coupled with religious and cultural attitudes towards organ donation that prevent people from signing up. Other areas of influence include age, education level and country of origin, all of which will be explored in this article, with the aim of looking at ways of promoting organ donation awareness and improving attitudes.

Methods

A structured questionnaire to uncover the awareness of and attitudes towards organ donation was devised and handed out to people on six different high streets in London with a predominantly Asian population – Tooting Broadway, Southall Broadway, Neasden High Street, Wembley High Street, Green Street and Harrow High Street. Interviews were carried out on Wednesdays and Saturdays over a three-week period, to obtain a varied sample from all backgrounds. Participants were all above 16 years of age (see Box 1).

Questions 6, 7, 16 and 18 (which assessed awareness) were combined to create a general 'awareness' variable. A second variable, which assessed attitudes, was created by combining questions 9, 10, 15 and 17.

The four potential influencing factors – religion, age, country or origin and education level – were each then tested against these two variables using the Chi-squared test, to see if there were any significant interactions between the demographic in question and awareness or attitude.

Results

Fifteen per cent of the total population were registered donors, 72% of whom carried a donor card,

Box 1. Questions asked in the survey of awareness and attitudes to organ donation

1. What is your age (under 26, 26–45 or 46+)?
2. What is your religion (Islam, Hinduism, Buddhism, Sikhism or Christianity)?
3. What is your country of origin (India, Pakistan, Bangladesh, Sri Lanka, Afghanistan, Nepal)?
4. What is your education (no qualifications, GCSE/A-level, university degree or higher)?
5. What is your current employment?
6. Are you aware of organ donation?
7. Are you aware that organs can come from live and deceased donors?
8. Please circle the organs you know can be donated: kidney, heart, liver, lungs, small bowel, pancreas.
9. Are you a donor? If so, how did you become a donor (not a donor, donor card, NHSBT website, community initiative, religious initiative, other)?
10. If you are not a donor, why not (personal choice, unaware of organ donation, against culture, against religion, did not know how to sign up)?
11. Do you have any family or friends registered as donors?
12. Do you have any family or friends who have had an organ transplant?
13. Do you have any family or friends that are awaiting an organ transplant?
14. Do you have any family or friends who are on a dialysis machine?
15. If someone close to you – a family member or a friend – required a transplant, would you donate one of your organs to them?
16. Are you aware that there is a severe shortage of Asian donors in the UK that is causing a threefold increase in waiting time for Asian patients compared with caucasian patients?
17. Does it bother you that South Asians have to wait three times longer for a transplant?
18. Are you aware that only 2% of donors on the register are from South Asian backgrounds?
19. Please list any groups, initiatives or people who are related to organ donation in any way.
20. What ways can we improve awareness about organ donation? Please list as many as you feel appropriate

20% having signed up through the NHS Blood and Transplant website and 8% through a community initiative. Of the 85% who were not donors, 35% claimed they were aware of organ donation, but it was their personal choice not to be a donor; 26% did not know how to sign up to be a donor; 18% said organ donation was against their religion; 10% said they were not aware of organ donation; and 7% said it was against their cultural beliefs.

When the question of donating to close family or friends was asked, only 62% of the population said they would donate an organ, while 75% of the population said it bothers them that South Asians have to wait three times longer for a transplant.

Results showed that an individual's country of origin had no significant influence on their awareness of, or attitude towards, organ donation. However, an individual's age and level of education did have a significant influence ($p<0.05$). Moreover, religion had a significant impact on attitudes towards organ donation ($p<0.05$) (see Table 1).

A total of 180 questionnaires were collected, of which 162 were fully completed. While 94% of participants were aware of organ donation, only 70% of these participants knew that donated organs come from both live and deceased donors. Only one-third of the population was aware that there is severe shortage of South Asian donors in the UK, and an even smaller percentage of people – 15% – were aware that only 2% of the registered donors are from a South Asian background.

To analyse the significant interactions further, the individual questions that comprised the general awareness and general attitudes variables were analysed, and Chi-squared tests were run on these (see Table 2).

It was found that age ($p=0.021$) and education level ($p=0.004$) had a significant influence on knowledge on the severe shortage of donors (question 16), as well as on people's knowledge that only 2% of donors are South Asian ($p=0.036$, $p=0.044$ respectively) (question 18) (see Table 3).

It was also found that religion had a significant interaction with questions 10 ($p=0.003$) and 15 ($p=0.01$), indicating that a person's religion significantly influenced why they were not a donor, and also whether they would donate an organ to a family member or friend.

Table 1. Chi-squared results for demographics on attitudes and awareness

Demographic and awareness/attitude	Chi-squared test value
Age and awareness	0.038
Religion and awareness	0.655
Country of origin and awareness	0.331
Education level and awareness	0.034
Age and attitude	0.829
Religion and attitude	0.011
Country of origin and attitude	0.227
Education level and attitude	0.203

Table 2. Chi-squared tests on significant interaction

Demographic and awareness/attitude	Chi-squared test value (significant values)
Age and awareness	0.021
Age and awareness	0.036
Education and awareness	0.004
Education and awareness	0.044
Religion and attitude	0.003
Religion and attitude	0.01

Discussion

Results show there is a distinct lack of awareness about organ donation, specifically of the shortage of donors in the South Asian community. This correlated with level of education: the more educated a person, the higher their awareness of organ donation. Religion was the biggest factor influencing attitudes toward organ donation. Participants of Islamic faith were most likely to be against organ donation. This matter can be discussed with various religious leaders to identify whether organ donation is permissible in their faith and, if so, relayed to the community to improve attitudes.

Since the level of a person's education was a significant factor influencing awareness, it is hoped that as the number of people of an ethnic minority going to university increases, so should the awareness of organ donation. However, education about organ donation can start earlier than it has done; some interviewees recommended starting 'organ donation road shows' in schools to teach about organ donation.

Table 3. Demographics of entire populations surveyed

Demographic	Age	Religion		Country of origin		Education level
Percentage (%) per group	Under 26 (36.4)	Islam (40.7)	Hinduism (37.7)	India (48.1)	Pakistan (12.3)	No qualifications (6.8)
	26–45 (46.3)	Buddhism (5.6)	Sikhism (9.9)	Bangladesh (13.0)	Sri Lanka (11.7)	GCSE/A-level/ BTEC/ National Diploma (29.0)
	46+ (17.3)	Christianity (6.2)	Other (0)	Afghanistan (12.3)	Nepal (2.5)	University degree or higher (64.2)

Interviewees also recommended ways to enhance the awareness of, and attitude towards, organ donations. Many people mentioned increasing publicity by sponsoring major Asian music and sporting events, such as international cricket. Many of the elder population said that increasing awareness could be achieved through adverts on Asian television networks and radio shows, while some advocated presentations at local places of worship.

Conclusion

Although there have been measures to increase awareness of the shortages of organ donation among the South Asian community through newspaper articles, research funding and NHS campaigns such as 'Real people, real lives, real action', there remains a distinct lack of awareness of organ donation and attitudes have remained negative. It remains to be seen whether there will be a change in attitude with future generations and whether schemes to increase awareness will have had a positive impact ■

Declaration of interest
None declared.

References
1. www.organdonation.nhs.uk:8001/ukt/campaigns/other_campaigns/detail.asp?id=3 (last accessed 01/08/12)
2. Department of Health. *Report of an independent review of specialist services in London*. London: HMSO, 1993.
3. Mather HM, Keen H. The Southall Diabetes Survey: prevalence of known diabetes in Asians and Europeans. *Br Med J* (Clin Res Ed) 1985; **291:** 1081–1084.
4. www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/national_audit_of_potential_donors.pdf (last accessed 01/08/12)
5. www.gmc-uk.org/static/documents/content/Gurch_Randhawa.pdf (last accessed 01/08/12)
6. Ahmed W, Harris S, Brown E. Attitudes to organ donation among South Asians in an English high street. *J R Soc Med* 1999; **92:** 626–627.

Key points

- The South Asian community makes up a mere 1–2% of the donors on the NHS organ donor register, despite the fact that this population group is more likely to require certain transplants, including kidney transplants.
- A structured questionnaire to uncover the awareness of, and attitudes towards, organ donation was devised and handed out to people at six different high streets in London with a predominantly Asian population.
- Results of the questionnaire show there is a distinct lack of awareness about the shortage of organ donors in the South Asian community. Religion was the biggest factor influencing attitudes toward organ donation.
- It is hoped that with improved education, awareness of organ donation within the South Asian community might be raised and attitudes towards it informed.