An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK

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Abstract Currently the demand for transplant organs far outstrips the supply in the UK. This problem is even more severe for the Asian population, who have been shown to be disproportionately over-represented on transplant waiting lists in some regions of the UK. Several commentators have suggested that religious and cultural traditions may be the major determinant preventing Asians from donating organs. An exploratory qualitative study was undertaken with the aim of examining the influence of religious beliefs, amongst other things, on the extent and direction of public attitudes towards organ donation in a cross-section of the Asian population in Luton.

This study indicates that, in the population studied, culture and religion play a much less prohibitive part in determining the level of organ donation than previously suggested. However, there is a desire to be aware of the religious stances so that people can make a more informed decision. The emphasis should clearly been a reconsideration of the presently inadequate approaches to organ procurement and on devising and supplementing these with more appropriate ones. An example of the failure to inform effectively the relevant populations about important developments is that only two of the 32 Muslims in the survey had heard of the ‘fatwa’ by the Muslim Legislative Council permitting organ donation.

Key words: Asian; organ donation; religion; transplantation

Introduction

At the end of 1996 there were over 6000 patients waiting for a transplant in the UK [1]. The vast majority of these people will continue to wait because of the severe shortage of donor organs. For the foreseeable future this trend is unlikely to change unless the number of donors is dramatically increased. This issue is even more pertinent to the UK’s Asian (those originating from the Indian subcontinent) population, who have been shown to be represented disproportionately more on transplant waiting lists in some regions of the UK [2–8]. This can be attributed to the higher incidence of end-stage renal failure as a result of increased rates of diabetes and hypertension among Asians [2,3,7–10]. Additionally, tissue type compatibility, and blood-group matching is more difficult across racial groups [3,6–8,11]. In the absence of accurate information, speculation about the factors determining the low rate of organ procurement among the UK’s Asian population pinpoints the religious beliefs of this population as possibly the primary influence in deterring Asian people from donating their organs [8,12,13].

An exploratory qualitative study was therefore undertaken to examine the issues pertinent to organ donation, one of which was the influence of religion, in a cross-section of the Asian population in Luton.

Subjects and methods

The fieldwork was divided into two stages using focus group discussions and individual interviews. Except for a pilot study conducted among a small sample of Coventry’s Sikh population carried out by Exley et al. in 1996 [13], this was, as far as we are aware, the first study to tackle the issue of organ donation among a cross-section of Asian communities. Consequently there were no pre-tested questions available for such a cultural setting. The aim of the focus group discussions was to identify any sensitive and complex issues. This information was then used to inform the household questionnaire.

A topic guide was produced for the group discussions in which the following areas were to be discussed: knowledge and awareness of transplantation; views of and attitudes towards organ donation.

Fieldworkers were recruited to conduct the group discussions and household interviews. The essential requirements were fluency in the relevant language, experience of socializing in and empathy with their ethnic community, being residents of Luton, interviewing and translating skills, and experience of group work. They were given training on conducting focus group discussions and interviewing in the Asian context.

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Bearing in mind that the group discussions were to be conducted in Asian languages, careful thought was given to the wording of the guide so that it could be easily translated into the relevant languages.

The study sample was selected on the basis of language and religion, and to reflect the demographic profile of the Asian population in Luton. These comprise:

- Gujarati-speaking Hindu women originating from India (Indian Gujarati);
- Punjabi-speaking Sikh women originating from the Indian Punjab (Indian Punjabi);
- Punjabi-speaking Muslim women originating from Pakistan (Pakistani Punjabi);
- Sylheti-speaking Muslim women originating from Bangladesh (Bangladeshi Sylheti);
- and four otherwise identical groups of men.

The group discussions

In total eight group discussions were conducted; one for each gender within the four populations. Single-gender groups were chosen to eliminate any inhibitions about discussing personal issues and perceptions about the body. The criteria for selection were gender, ethnic origin, religion, language spoken, and age.

The group discussions included people ranging in age from 18 to over 60 years. It was therefore essential to have fieldworkers who were fluent in English and their mother tongue and the discussions were conducted in both, as the need arose. Sometimes some parts of the discussions were immediately translated by the fieldworker for those whose main language had not been used [14]. This was viewed as a natural process to the functioning of the group and did not disrupt the discussion. The discussions were moderated by the fieldworkers with one of the researchers present in a supporting role, taking part in directing the discussion if required [15]. A female researcher was present at the female group discussions, whilst at the male group discussions the male researcher (GR) attended.

The venues for the discussions ranged from the University, community centre, a school, and the moderators’ homes. The major determining factor for the choice of venue was convenience for all those participating. Each of the group discussions was tape-recorded and then transcribed into English by the fieldworkers within a couple of days. Prior permission for recording was obtained from all participants. The findings from these group discussions were used to inform the household questionnaire.

Devising the questionnaire

The draft questionnaire consisted of a number of modules:

- Background to the study;
- Demographic information;
- Perceived position of religion towards organ donation;
- Views concerning organ donation.

The questionnaire was developed using the Health and Lifestyles Survey questionnaire, Black and Minority Ethnic Groups in England—Health and Lifestyles Survey questionnaire, and the General Household Survey questionnaire [16,17]. These questionnaires were particularly useful when devising the format and developing the demographic information section of the questionnaire. A major concern when considering the format of the questionnaire was to the wording of the questionnaire so that it could be easily translated into the relevant languages. The group discussions were invaluable in identifying any problematic terms or words that would have to be explained with more clarity in the questionnaire.

Piloting

The questionnaires were piloted by each of the fieldworkers. All the fieldworkers carried out two interviews and were asked to encourage the respondents to be interviewed in their mother tongue in order to make sure that the questionnaire was tested in all languages. After this process, some of the questions were rephrased to make their understanding clearer.

Choosing the sample

While conducting a detailed qualitative study, it was nevertheless important for us to select a sample that enabled a cross-section of views to be represented.

The settlement pattern of Asians in the UK has resulted in their concentration in mainly urban locations. Within the large towns and cities the settlement has occurred in fairly small areas. This pattern of settlement has allowed researchers to cluster their sampling in enumeration districts, for example, with relatively high concentrations of Asian populations [18]. A similar approach was taken recently by the Health Education Authority’s Health and Lifestyles Survey [17].

The concern with focused sampling is that the survey, although broadly representative of the groups under study, gives only a range of views of those living in areas of high migrant settlement, who may have different social and demographic characteristics from those in areas of low settlement [19]. The important consideration is for researchers to be aware of these limitations and their effects on the survey results.

Due to the small sample size and exploratory nature of the study, it was decided that these were not major impediments. The 1991 Census was used to identify four wards in Luton which contained the highest proportion of Asians (Biscot, Dallow, Saints, and Chaliney respectively).

Three samples of addresses were then drawn randomly (one for each religious group: Hindu, Muslim, and Sikh) using the electoral register by analysis of names. The electoral register lists for each household the names of people aged over 18 years who are UK or Commonwealth citizens. Sampling from these registers has been used to identify Asians for population surveys [19,20]. This method is especially useful when studying South Asians, as Hindu, Muslim, and Sikh names are easily identifiable. A problem with this method, however, is that it is difficult to distinguish between Bangladeshi Muslim and Pakistani Muslim names, since most are of Arabic origin.

A wide range of different languages are spoken by people of Asian origin, some regional languages not having a written form [17]. Regional rather than national languages were used to conduct the interviews, the aim being to interview people in the languages they spoke at home to ease communication and facilitate discussion [17].

The three samples based upon religion were now subdivided in terms of language spoken. The language of most
relevance in Luton for Hindus is Gujarati; for Sikhs it is Punjabi; and for Muslims it is Punjabi (Urdu) or Sylheti depending on whether they are Pakistani or Bangladeshi respectively. This gave four samples—Gujarati, Punjabi, Punjabi (Urdu), and Sylheti. In order to distinguish between Bangladeshi and Pakistani names, representatives from the local Bangladeshi Mosque and Pakistani Mosque assisted.

Each sample thus contained 80 addresses of 40 men and 40 women, within which the male and female fieldworker for each language group was to carry out the interviews. Each of the fieldworkers was required to complete a quota of eight interviews, with a total of 64 interviews. The selection criteria were two respondents from each of the following age groups: 18–25, 26–40, 41–65, 65+.

It was felt that this age and gender profile would give us as broad a cross-section of views as possible within the limits of the study.

**Fieldwork**

Letters were sent out to all of the addresses selected, in both the relevant mother-tongue and in English. These contained a short background to the study and requested voluntary participation. The prospective respondents were informed that a fieldworker of their gender and speaking their language would be calling upon them in the next few days to arrange a suitable time for an interview if they wished to participate. All fieldworkers were provided with a University identity card and a personal security alarm for safety reasons.

The sample was selected so as to include equal numbers of respondents from the four different language groups: Sylheti, Gujarati, Punjabi, and Urdu. The ethnic and linguistic spread of the sample was such that three major religious groups were represented: Hindus, Muslims, and Sikhs. Interviews were conducted in the respondents’ first language, and written on to each questionnaire in English [14]. Interestingly, once face-to-face contact had been made, there were very few refusals to participate. It was also significant to note, contrary to some stereotypical views of gender relationships, that the female fieldworkers encountered no difficulties in approaching women directly in households.

**Results**

Naturally, the conclusions drawn from the analysis which follows apply to this sample alone and cannot be generalized in a straightforward manner to the wider UK population of Asian communities. As the study involves small and statistically unrepresentative samples, elaborate statistical analysis of the survey findings has not been attempted. Nonetheless, this approach highlights themes and trends in the data that allow speculation about the wider populations at large. It would be possible, for example, to suggest the relevance in Luton for Hindus is Gujarati; for Sikhs it is Punjabi; and for Muslims it is Punjabi (Urdu) or Sylheti depending on whether they are Pakistani or Bangladeshi respectively. This gave four samples—Gujarati, Punjabi, Punjabi (Urdu), and Sylheti. In order to distinguish between Bangladeshi and Pakistani names, representatives from the local Bangladeshi Mosque and Pakistani Mosque assisted.

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The majority of respondents (38 of the 64) said they did not know what their religion prescribed in terms of organ donation; only most people of the Sikh faith felt confident that their religion viewed it positively. This was not due to any edict having been passed but as a deduction from the humanitarian principles taught in their faith. Twelve of the 16 Sikh respondents said they would donate their organs after death as opposed to other groups in which indecision and a desire for more information was expressed.

Only two of the 32 Muslim respondents had heard of the ‘fatwa’ passed by the Muslim Law Council in 1995 [12]. Clearly the publicity campaigns which highlighted the ‘fatwa’ had not utilized effective channels of communication for informing the Muslim population. The Muslim respondents in this survey was a group that relied particularly heavily on the religious prescriptives in their faith to direct their beliefs and behaviour towards organ donation. Rather than relying solely on their own conclusions regarding the issue, they were awaiting a decision by the Ulema to provide guidance as a precedent on this contemporary issue:

‘If the religious leaders give us a clear-cut opinion on this matter then we have less confusion. Religion is for people to live well; it shouldn’t be an obstacle to something positive like organ donation. More discussion and information will help us to proceed in this direction.’

I intended to carry it but we have some superstitions or beliefs, I don’t know which. We don’t know much about it, whether organ donation is right or wrong. Some say it is right, some are against it. Some say just an eye or any organ can be donated by a person during his lifetime.’

One respondent, however, said:

‘I haven’t read about organ donation in the religious literature but my heart tells me it is not right. With us, only close relatives, no more than four, should touch the body (to wash it) and place it in the grave.

Another respondent commented that he had studied the Qur’an and deduced that organ donation was permissible.

Only four of the 32 Muslim respondents had stated categorically that they thought Islam was against organ donation, and two thought it was regarded favourably. Indecision or unwillingness to donate for reasons connected with religious belief or practice were, however, not limited to Muslims. A Sikh male commented:

‘I want to be in peace when I am cremated.’

A Hindu male remarked:

‘I would not donate my eyes, ever, because of the ceremony prior to cremation when people come to the funeral to see the body. I don’t want to not have any eyes.

Quotations have been reproduced verbatim and no changes have been made for grammatical or other reasons.
A comment by a Hindu male serves as an example of the sentiments expressed by the majority of all respondents grappling with whether organ donation was in accordance with the beliefs of their faith:

‘Our religion says do not waste things; if they can be utilized and used for the good of other people, then that item should not be thrown away.

**Other variables affecting organ donation**

Comments made by a few respondents suggest a cautious attitude towards organ donation as a result of ignorance of the procedures involved in transplantation activity:

‘Do they take organs out as someone is dying?’ BW
‘Does taking organs take place before or after death?’ PM
‘I’m worried about someone taking my organs out while I’m still alive. It goes on.’ SM

The main reasons for the majority of people not deciding to donate their organs was that they had not given the issue serious thought and because, particularly for Muslims, they did not know what their religion’s stance was on the subject. The range of responses also included thoughts and fears common to people of all populations:

‘I don’t know, I don’t have enough information’ PM
‘In a couple of years I might agree to donate. I may change my mind. I mean people in hospital are donating blood on request.’ BM
‘I am willing to donate. It’s a serious issue and as a Muslim, I want to know if there would be any religious objection to it. If not then I will donate. Similarly, I would accept an organ too. Who doesn’t want to live longer?’ BM
‘I’m not sure about life after death, but if there is life I want to go complete.’ SW
‘I don’t like the idea of someone cutting me up.’ GW
‘I don’t like the idea of my relatives having to see my body having been carved up.’ GM
‘I don’t like the idea of my organs living in another body, it may affect their personality and make them more like me.’ SW
‘On the one hand it’s a good thing to help others but on the other hand our bodies are specific to ourselves. How can it be good to mix your body with another? I can’t distinguish what’s good or bad in this case, there are no absolutes.’ PW

Of the people who would donate, some reticence was expressed by a few respondents only in donating their eyes. This was mainly related to how they would look before their burial:

‘I would look ugly without my eyes and anything visible.’ SW

A few elderly people, willing to donate, thought there was not much point in making the offer as their organs were so old by now and of little use to anyone else.

Approximately half of the respondents said they would accept an organ if they needed one. The rest either would not accept or hadn’t thought about it, a number adding that the question was hypothetical and it was difficult to say what they would do in the circumstance. In accepting an organ, all organs were acceptable though a few had reservations about accepting someone’s eyes:

‘Someone else’s eyes may make me look different.’ SW

When those who would accept organs were asked whether there were people they would not accept organs from, half of the respondents said they would accept from anyone:

‘I think when you are in that situation you would not care where the organ came from.’ GW
‘If a man is hungry you don’t look at who is giving the food, similarly with organs.’ GM

A quarter of the respondents did not comment and a quarter had individual reasons that indicate, for some people, a preference for organs from those with whom they have a biological or sociocultural bond:

‘I would not feel comfortable unless it was a member of my community.’ GW
‘Not someone outside my community, other people’s beliefs and culture are different.’ SW
‘I would want the heart of a Muslim. These are my feelings. Maybe all hearts are the same. If it’s to be a male donor then I would prefer someone from my immediate family.’ PW
‘Not an English person. I don’t know much about their beliefs and culture. The only thing I know is that they are too open. They let their children out young and marry and divorce many times. They smoke and drink.’ SW
‘Not a Muslim. Because of what our history says they did to Muslims.’ SW

Virtually all interviewees said they would respect the wishes of a deceased relative who had expressed the desire to donate their organs before death. Of those who were not sure, one Muslim woman commented:

‘If the Ulema clarified the issue and it was permissible in Islam I would give my consent. I would not do something that is not allowed in my faith.’

Another respondent said:

‘I would only give my consent if the wish (to donate) was expressed in writing, not just verbally.’

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2 Codes are used after quotations to indicate the study group in question. i.e. ‘BW’ refers to Bangladesh women, ‘GW’ refers to Gujarati women, ‘PW’ refers to Pakistani women, ‘SW’ refers to Sikh women, and ‘BM’, ‘GM’, ‘PM’, ‘SM’ for the respective male groups.
If a relative died and had given no indication of whether their organs were to be donated, approximately half of the respondents would give their permission for the organs to be transplanted. Some said they had never thought about it. The majority of Muslims felt they did not have the authority to make such a decision on behalf of the deceased, though a couple said they would give permission:

‘If someone needs it and it can be useful, then yes.’ PM

‘The dead person wouldn’t need them and it would benefit someone else.’ SM

A number of people mentioned that it was difficult to answer the question as, in the context of their culture, such a decision would not be taken by an individual alone, but would involve various members of the family:

‘There are too many people involved around the dead person normally. You’d have to ask the head of the household who’s normally the oldest person and probably against the idea or not used to the idea of donation.’ SW

‘There are other relatives involved who may be against the idea of donation. In our culture it’s not an individual, but a group decision.’ SW

Two people’s families had been approached for organs when a relative of theirs had died. One, a Muslim family, gave their consent as the person had a donor card. In the second case a Sikh lady commented:

‘Somebody did approach our family, but I was in no state to answer any questions.’

Discussion

This short exploratory study has provided a ‘snapshot’ picture of the experience of Asians in Luton with regard to organ donation and the influence of religion. By sampling purposively and making the different Asian communities the focus of the research, this study looks to advance our currently very sketchy knowledge of these communities’ views towards organ donation. The study should be seen as exploratory, but is nonetheless an important initial step towards the establishment of a greater knowledge and understanding of the issues affecting the low donation rate in the Asian population.

In order to understand the context of people’s responses it is important to review the literature concerning organ donation and religion. None of the religions object to organ donation in principle although in some there are varying schools of thought. The recent ‘fatwa’ (edict) from the Muslim Law Council has clarified much of the divergence in opinion among Muslim commentators [12]. This directive states that it is permissible to donate organs, and accepts brain-stem death as an acceptable diagnosis of death. There is nothing in Hindu scriptures to indicate that organs cannot be donated to alleviate the suffering of other people. Some Hindu commentators, however, have proposed that donation is only acceptable if the desire to donate is expressed overtly before death [21]. There is no religious prohibition against organ transplantation in Sikhism or Buddhism [22]. In Christian belief, organ donation is acceptable if prior consent has been obtained either from the donor while alive and/or the donor’s next of kin [23]. Thus none of the religious faiths adhered to by most Asians prohibit organ donation.

In the population studied, religious prescriptives were important to many Asian people, especially Muslims. People wish to be informed of the religious stances so that they can make a more informed decision. Transmission of this knowledge would certainly facilitate the decision-making process for people to whom the stance of their faith is an important issue. An example of the failure to inform effectively the relevant populations about important religious developments is that only two of the 32 Muslims in the survey had heard of the ‘fatwa’ by the Muslim Legislative Council permitting organ donation. This was despite the publicity it had received. Publicity of the ‘fatwa’ was limited to a news item on the morning edition of Radio 4; television coverage on the evening news in the Midlands area, from where the ‘fatwa’ had been initiated; and limited coverage in two Asian newspapers. It is obvious that the publicity campaign was not utilizing effective channels of communication for informing the Muslim population. Mass media is used to dispense information to large numbers of people quickly. However, there are various forms of media and one needs to select those appropriate to the target group and the message that one wishes to convey.

This study indicates that, in the population studied, culture and religion play a much less prohibitive part in determining the level of organ donation than previously suggested. However, there is a desire to be aware of the religious stances so that people can make a more informed decision. The emphasis should clearly be on a reconsideration of the presently inadequate approaches to organ procurement and on devising and supplementing these with more appropriate ones.

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References


