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Awareness and attitudes towards organ donation and transplantation among the Asian population

A preliminary survey in Luton, UK

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Abstract Currently the demand for transplant organs, particularly kidneys, far outstrips the supply in the UK. This problem is particularly severe for the Asian population, which has been shown to have a disproportionately large representation on kidney-transplant waiting lists in some regions of the UK. The situation is clear: there is an urgent need to address the number of Asians requiring a kidney transplant, otherwise the human and economic costs will be very high. An exploratory qualitative study was therefore undertaken with the aim of assessing current awareness of organ donation and transplantation and to explore attitudes towards these issues in a cross section of the Asian population in Luton. It was found that nearly half of the respondents in this survey did not know what a donor card was used for, and approximately half of these had never seen one; only 6 of the 64 people interviewed had heard of the National Donor Register. Of the three people who

carried a donor card, two had an immediate family member who had received a transplant. This suggests that media campaigns aimed at attracting donors from the Asian population have had limited success thus far. It appears that the vast majority of the Asian population is at the initial stage of the process of making a decision about donating their organs, that of simply knowing that transplantation takes place. Very little debate of pertinent issues seems to have taken place, which is essential for reaching a decision on whether or not to donate an organ. 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.

Key words Asians · Attitudes · Donation · Knowledge · Transplantation

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Introduction

Donated organs are matched to patients by characteristics such as tissue type, blood group, age and weight. For identifying a suitable kidney, the most important factor is the tissue type, which is more complex than blood grouping. The more accurate the match the better

the chances of success [21]. Unfortunately the opportunity for a kidney transplant is not available to all people, as this is influenced by the increasing demand for a limited supply of suitable organs. This situation is particularly alarming for the UK's Asian (those defined as from either Bangladeshi, Indian or Pakistani origin) population, with their higher susceptibility to end-stage

renal failure (ESRF), which has resulted in a higher uptake of renal replacement therapy (RRT) [6, 16, 20]. Asians make up 2.7% (1,480,000) of the total population: Bangladeshi origin, 0.3% (163,000); Indian origin, 1.5% (840,000); and Pakistani origin, 0.9% (477,000) [15]. Yet the proportion of Asians on kidney-transplant waiting lists is growing rapidly; it is more than 25% in some regions [6, 12, 13, 19, 20]. Coupled with this are problems of histocompatibility and blood-group matching, which has led to longer waiting times for a transplant [7, 12, 13].

The situation is clear: there is an urgent need to address the number of Asians requiring a kidney transplant, otherwise the human and economic costs will be very high. The review of national renal services estimated the annual mean cost per patient on dialysis at £ 23,000. In the long term, the transplant option is more economically desirable, as the initial cost of the operation is £ 12,000, with recurring annual costs of about £ 5,400 for drugs and other treatment [9]. These financial pressures will continue upon the National Health Service unless appropriate preventive strategies are implemented.

In the short term, there needs to be a greater number of donors coming forward from the Asian communities to increase the pool of suitable organs which can only be achieved by increased donor card carrying and signing the donor register [7, 17]. The register was launched in 1996 and consists of names of donors who have given express consent. Every transplant co-ordinator has instant access to the register [17].

Only very recently have specific attempts been made to attract donors from Asian communities using "ethnic mass media". The Department of Health has produced material to increase awareness of transplant-related issues in four of the main Asian languages (Punjabi, Urdu, Hindi and Bengali). Donor cards and leaflets related to the Donor Register are available, as is a short video entitled "Organ Box", which highlights the need for donors. These measures, however, are going to have little impact unless the issue of dissemination is addressed more seriously.

An exploratory qualitative study was therefore undertaken in relation to issues connected with organ donation. The aims of the study were as follows: to assess current knowledge and awareness of organ donation and transplantation among Asians; and to explore attitudes to transplantation and organ donation.

Methods

The fieldwork was divided into two stages using focus group discussions and individual interviews. The aim of the focus group discussions was to identify any sensitive and complex issues. This information was then used to complete 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; and 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 socialising 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. 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 the language spoken and religion and was designed to reflect the demographic profile of the Asian population in Luton. These comprise:

- Gujarati-speaking Hindu women originating from India (Indian Gujarati; GW)
- Punjabi-speaking Sikh women originating from the Indian Punjab (Indian Punjabi; SW)
- Punjabi-speaking Muslim women originating from Pakistan (Pakistani Punjabi; PW)
- Sylheti-speaking Muslim women originating from Bangladesh (Bangladeshi Sylheti; BW)
- Four otherwise identical groups of men; BM, GM, PM, SM

The group discussions

In total eight group discussions were conducted; one for each sex within the four populations. Single-sex 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 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 [4]. 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 [14]. The female researcher (A.D.) was present at the female group discussions, whilst the male researcher (G.R.) attended the male group discussions.

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 were 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 complete the household questionnaire.

Devising the questionnaire

The draft questionnaire consisted of a number of modules: background to the study; demographic information; knowledge and awareness of transplantation; views of and attitudes towards 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 [10, 11]. 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 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 [11].

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 [5]. 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 the four wards in Luton that contained the highest proportion of Asians (Biscot, Dallow, Saints and Challney, 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 [5, 22]. This method is especially useful when studying southern 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 [11]. 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 [11].

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 (40 men and 40 women) from which the male and female field-worker for each language group was to carry out the interviews. Each of the fieldworkers was required to complete a quota of 8 interviews, with a total of 64 interviews. The selection criteria were two respondents from each of the following age groups: 18–25 years, 26–40 years, 41–65 years and 65+ years. 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 purposively 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, the interviewer sight-translating the questions during the interview. Open-ended responses were translated and written on to each questionnaire in English [4]. 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 that follows apply to this sample alone and cannot be generalised 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 that allow for some speculation about the wider populations at large.

Knowledge and awareness of transplantation-related issues

Transplantation

Results from the interviews revealed that in this Asian population there is a general awareness that transplantation of organs takes place; only 10 of the 64 respondents had not heard of it. The majority were also aware of live kidney donation. The sources of basic information on the occurrence of transplantation were varied; the main ones being the television, followed by local community radio and leaflets in GPs' surgeries. In this

context, however, a greater influence on the level and depth of information that people have has been the prevalence of transplant-related situations in the community. Twenty-three of the sixty-four respondents knew of someone who had undergone a transplant, ten were aware of a person who had died needing a transplant and ten knew of someone waiting for a transplant. Although personal knowledge of this kind is predominantly of people in England, the experiences related by respondents included people and events in the Indian subcontinent. Half of the respondents were aware of the shortage of organs. They were also mainly those who knew of people with a transplant-related experience. Three-quarters of the respondents had heard of the trade in human organs and virtually all regarded it with distaste.

Donor cards

Over half of the study sample knew what donor cards were. One-quarter, however, did not know what a donor card was used for and half gave the reason for not carrying a donor card as not having given it much thought. Only three people carried a donor card, all of whom were Sikh women. Two of these women had experience of an immediate family member requiring a transplant. Only five people had heard of the National Donor Register; all of those who had heard of it mentioned "on TV in the English language".

Attitudes towards 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)¹
- "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 main focus was that they did not know, not that their religion forbade organ donation.

¹ Quotations have been reproduced verbatim and no changes have been made for grammatical or other reasons

tion. 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." (SF)
- "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 now and of little use to anyone else.

Sources of health information

When asked where they received general health information, television was cited as the main source, followed by community radio, community newspapers and leaflets in GPs' surgeries. Documentaries, and medical dramas such as *Casualty* and *Great Ormond Street* were mentioned as being informative. The information was received predominantly in English. Information in the mother tongues has been received mainly from community newspapers and leaflets in GPs' surgeries.

The most appropriate way to inform about organ donation

The respondents were asked what, in their opinion, was the best way of informing them about issues related to transplantation. Television was mentioned by all of those interviewed, as were community radio and community newspapers. The need for the information to be available in both mother tongue and English was expressed with regard to community newspapers and radio.

Discussion

This short exploratory study has provided a "snapshot" picture of the experience of Asians in Luton with regard to organ donation and related issues. The findings show that most of our interviewees were aware that procurement and transplantation of organs takes place from the cadaver as well as live kidney donation. Any knowledge beyond this was mainly among people who knew of someone with a transplantation-related experience and had been received through informal community networks. Nearly half of the more informed respondents were aware of the shortage of organs. In the absence of data on the prevalence of transplantation activity among Asians, it is not possible to conclude that people's awareness of transplantation is due to a very high prevalence of the occurrence or need for such operations in this population. However, the above situation does reflect the important role of community networks in the transmission of health information within this population. This function of informal community networks has also been noted in a study by Darr (1990) of the family-experience and service-delivery implications of thalassaemia for British Pakistanis [3]. The study found that health information imparted in a culturally sensitive manner to a core number of families travelled swiftly to families in other parts of England whose children had the same condition; the channels of information proved to be the already-established kinship networks specific to Pakistanis. Although the various sub-groups within the Asian population do not share the same kinship patterns, nevertheless there are also other networks, which have been formed by caste and religious affiliations.

It seems that detailed information related to transplantation activity such as a shortage of organs, dialysis, whether donors or recipients survive and so forth has been learned through the experience of people within the community and has been transmitted through these various informal networks. Given this situation, wherein community networks are already established and around which there is also some social organisation, it would appear that the successful grass roots approach,

incorporating face-to-face dialogue and an ethnically directed message, advocated by Callender (1989) and Hall et al. (1991) among African-Americans in the USA, may have some relevance for Asians in the UK [1, 8]. This initiative in the USA has expanded to other ethnic minority groups and is based upon the principles of community education, community empowerment, and utilising culturally and ethnically sensitive messengers [2]. A similar approach in the UK may prove to be fruitful.

The rationale behind media campaigns on organ donation is to inform the public about the existence of transplantation, the need for organs and how the public can indicate their decision to donate through carrying a donor card or registering on the National Donor Register. The limited success of campaigns to date is reflected in the fact that nearly half of the respondents in this survey did not know what a donor card was used for and approximately half of these had never seen one; only six people had heard of the National Donor Register. Of the three people who carried a donor card, two had an immediate family member who had received a transplant. Current evidence suggests that there has to be a multi-source approach, as people have access to different sources of information and therefore each of these needs to be utilised.

It appears that the vast majority of the Asian population is at the initial stage of the process of making a decision about donating their organs, that of simply knowing

that transplantation takes place. Very little debate of pertinent issues seems to have taken place, which is essential for reaching a decision on whether or not to donate an organ.

The aim of this intensive study was to examine the awareness of, and attitudes towards, organ donation among Asians in Luton. 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.

Further research is needed, however, to verify these findings, since this study is the first to investigate knowledge and attitudes to organ donation within a cross section of the Asian population. As stressed earlier, the Asian population is extremely heterogeneous and future investigations should have larger samples comprising different socio-economic groups, to reach all communities. Consideration should be given to conducting this research using local studies throughout the UK in order that any regional differences may be ascertained. The findings of these studies, in addition to enhancing our understanding of the elements or factors that govern the willingness of Asians to consider donation, may be used in formulating a detailed strategy to encourage Asians to become organ donors.

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