



UNIVERSITY OF LEEDS

This is a repository copy of *The meanings of organ donation : Muslims of Pakistani origin and white English nationals living in North England* .

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/1478/>

Article:

Hayward, C. and Madill, A. (2003) The meanings of organ donation : Muslims of Pakistani origin and white English nationals living in North England. *Social Science and Medicine*, 57 (3). pp. 389-401. ISSN 0277-9536

[https://doi.org/10.1016/S0277-9536\(02\)00364-7](https://doi.org/10.1016/S0277-9536(02)00364-7)

Reuse

See Attached

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>



White Rose
university consortium
Universities of Leeds, Sheffield & York

White Rose Consortium ePrints Repository

<http://eprints.whiterose.ac.uk/>

This is an author produced version of a paper published in **Social Science and Medicine**.

White Rose Repository URL for this paper:

<http://eprints.whiterose.ac.uk/archive/1478/>

Published paper

Hayward, C. and Madill, A. (2003) *The meanings of organ donation : Muslims of Pakistani origin and white English nationals living in North England*. *Social Science and Medicine*, 57 (3). pp. 389-401.

Hayward, C., & Madill, A. (2003). The meanings of organ donation: Muslims of Pakistani origin and white English nationals living in North England. Social Science & Medicine, 57, 389-401.

The meanings of organ donation:

Muslims of Pakistani origin and white English nationals living in North England

Clare Hayward, M.Sc., Academic Unit of Psychiatry, 15 Hyde Terrace, University of
Leeds, Leeds, LS2 9JT, UK

* Anna Madill, Ph.D., Lecturer, School of Psychology, University of Leeds, Leeds,
LS2 9JT, UK

Telephone: 44 + (0)113 343 5750

Fax: 44 + (0)113 343 5749

E-mail: annam@psychology.leeds.ac.uk

Running head: The meanings of organ donation

* Corresponding author

ABSTRACT

This study explores the meanings of organ donation, with emphasis on donating eyes and hearts, comparing people across gender and across two ethnic groups. Four focus group interviews were conducted with people living in the North of England: (1) five Muslim women of Pakistani origin, (2) five Muslim men of Pakistani origin, (3) nine white English women, and (4) eight white English men. The focus group interviews were analysed using grounded theory and a conceptual micro-model created for each group. The main finding was that the act of organ donation can be perceived as involving a personal cost. The Muslims of Pakistani origin related costs with their religious beliefs. In contrast, the white English associated costs with their distrust of the medical system. Women were concerned about the transmission of disease or of personality, whereas the white English men highlighted their personal rights. We conclude that the meaning of organ donation is more than about being and having a body. It is bound up in metaphors of embodiment, religious considerations, and moral judgement of scientific and medical conduct.

KEY WORDS

organ donation, Islam, grounded theory, embodiment, gender, health, Pakistanis, Muslims

The Meanings of Organ Donation:

Muslims of Pakistani origin and white English Nationals Living in North England

Organ donation can occur during a donor's lifetime or after his or her death and recent advances have increased the feasibility of xenotransplantation; the replacing of human organs with those of animals (Derenge & Bartucci, 1999). However, at the present time, the success of transplantation relies on the willingness of the public to donate their organs or those of recently deceased relatives. And a major problem in the United Kingdom is the dwindling numbers of cadaver donor organs in proportion to people waiting transplant (UK Transplant Support Service Authority, 1999).

According to three UK surveys (New, Solomon, Dingwall & McHale, 1994), 70% of the population are willing to donate but only 27-32% carry an organ donor card. Men and women show similar willingness to donate but women are twice as likely to carry a card. Moreover, 10% of those who carry a card place restrictions on their donation; 85% are not prepared to donate their corneas and 18% do not wish to donate their heart (UKTSSA, 1999). Interestingly, women are less likely to donate either of these tissues than are men (Wilms, Kiefer, Shanteau & McIntyre, 1987). Studies of organ donation decisions also suggest that the eyes and heart are special in that bereaved relatives often refuse these organs for donation (e.g., Fulton, Fulton & Simmons, 1977). Shanteau and Harris (1992) speculated that reluctance to donate may not be due to lack of knowledge or empathy per se but to 'unstated motivations, perceived risks and unarticulated fears' (p.2). Hence, the meaning of carrying an organ donor card or of donating specific body parts, particularly the eyes and heart, may be complex and have different meanings for men and women.

In the UK there is very little literature on cross-cultural differences in organ donation. Ahmed, Harris and Brown's (1999) survey suggests that only 16% of South

Asians living in the UK carry an organ donor card. Moreover, in the most recent audit, only 2% of Muslims were recorded as having consented to donation (Transplant Co-ordinators Association, 1995). Muslims had been more likely to refuse to donate than other religious group, apart from Sikhs and Jehovah's Witnesses, but were also the least likely to have been approached with such a request by health service employees.

In Exley, Sim, Reid, Jackson and West's (1996) pilot study of Sikhs living in the UK, barriers to transplantation related more to knowledge and understanding than religious or cultural factors. Randhawa's (1998) research on Sikh, Muslim, and Hindu populations in Luton also indicates that religious and cultural factors play a much less prohibitive part in organ donation than had previously been thought for Asian groups. Nonetheless, Randhawa's findings also suggested that, particularly for Muslims, an awareness of their religion's stance towards organ donation was an important influence (see also Sheikh & Dhimi, 2000). However, few of his Muslim participants were aware of the Fatwa, (a religious edict, but one that is not binding) issued in 1995 by the Muslim Law Council in support of organ donation.

The British Muslim community is ethnically and culturally heterogeneous (Anwar, 2000). We selected Muslims of Pakistani origin living in North England for comparison with white English nationals from the same locale as Muslims of Pakistani origin represent the largest sub-group of Muslims living in the UK. The views of Muslims of Pakistani origin about organ donation are chronically under-researched even though British Asians have three times the risk of the white population of suffering renal disease (Roderick, Raleigh, McGowan & Mallick, 1994). Moreover, the low number of British Asians carrying an organ donor card means that Asians often have to wait 10-12 months longer than their white

counterparts for a kidney transplant due to the necessity of blood group matching (Carlisle, 1995).

The main focus of organ donation research has been on people's attitudes and beliefs (e.g., Batten, 1992; Kopfman & Smith, 1996). Such studies have usually been survey-based using pre-defined criteria. Hence, what is found is limited by the questionnaire used and constrained by the researcher's frame of reference. An alternative is to use a qualitative, interview-based approach. However, where qualitative methods have been adopted in organ donation research it has often been in the form of descriptive, single case studies (Bartucci & Bishop, 1987; Basch 1973).

Grounded theory (Glaser & Strauss, 1967) was selected as the method of analysis. It is a rigorous, well-established qualitative approach that seeks to generate a conceptual understanding (theory) from a bottom-up analysis of textual data (i.e., it is 'grounded'). This approach is particularly suitable for research on topics about which little is known or where it is practically or ethically difficult to control variables and test hypotheses. Its discovery-orientation also makes it appropriate for research seeking to elucidate participants' own understandings and has already been used to good effect to explore the experience of the relatives of cadaver organ donors (Sque & Payne, 1996). Focus group interviews were used to generate data as it was considered this format would encourage participant debate and, hence, draw out the complexities of meaning surrounding organ donation.

In summary, the present grounded theory study explores the meanings of organ donation, with particular emphasis on donating eyes and hearts, comparing people across gender and across two ethnic groups.

METHOD

Ethical Approval

Ethical approval was granted by the Ethics Committee, School of Psychology, University of Leeds, UK. Permission was granted by the organisations from which participants were recruited, informed consent obtained from all participants, and pseudonyms used throughout this report.

The Researchers

Both researchers are white British females who are broadly supportive of organ donation. Both have in the past carried an organ donor card and AM has placed her name on the Organ Donor Register.

Participants

Five Muslim women of Pakistani origin, five Muslim men of Pakistani origin, nine white English women, and eight white English men participated in the main study (table 1). People between 27 and 50 years old were selected in order to increase the opportunity of sampling those who held a donor card (New et al., 1994). One Muslim man (born outside the Leeds-Bradford area) and two Muslim women were second generation migrants to the UK. The other Muslim participants were first generation migrants. Of the white English, 29% carried a card, which is similar to that of the general population. No Muslim participant carried a card, although three indicated that they would be willing to do so and two had done so previously which, if taken into account, makes this sample comparable with the UK South Asian population (Ahmed et al., 1999). A range of social economic status (SES) was sampled and, as far as possible, white English participants were matched on SES with respect to their Muslim counterparts (Black, Townsend, Davidson & Whitehead, 1988).

-----table 1 about here-----

Muslim women were recruited through community centres, as were the majority of white English women. Having secured quickly the interest of several

women, recruitment proceeded through a snowball effect so that in the end about 30 Muslim women and 25 white English women volunteered. Common issues for declining participation were lack of child care or spare time, reticence to be part of a discussion group, and for the Muslim women, uncertainty about Islam's position on organ donation and/or lack of fluency in English. It proved more fruitful to recruit Muslim men through word-of-mouth helped by the husband of a Muslim colleague. The Muslim men who did not wish to attend did not have enough time to spare or had required more notice. A local fire station provided four of the white English men with the others recruited face-to-face and through word of mouth, accepting those who were good SES matches to the Muslim men from the 20 volunteers found. White English men who declined did not want to be part of a discussion group, thought the topic morbid, or that talking about the subject might bring them bad luck. Around ten individuals were invited to participate in each group (Berg, 2001). As we considered it unethical to re-contact non-attenders, we are uncertain why the number of Muslim attendees was a little disappointing.

Data Collection

A semi-structured interview schedule was piloted. For ease, two mixed-sex but ethnic-specific pilot focus groups were used and the target age range relaxed. The Muslim pilot group was recruited from an Urdu night class and the white English pilot group were undergraduate students. The open-ended questions focused on main themes in the literature; influences on carrying an organ donor card, reactions to signing a card, fears about donation, reticence to donate eyes and hearts, influence of age, family, friends, and religion, moral issues, and feelings about receiving organs. Following the pilot focus groups, minor alterations were made to clarify original questions and new questions were added on live and on animal organ donation as

these topics were raised by pilot participants. Participants in the main study were interviewed in one of four gender- and ethnic-specific focus groups, i.e., one group each of Muslim women, Muslim men, white English women, and white English men. These distinctions were maintained to allow the development of separate analyses as the aim was to compare across gender and ethnic group.

Analytic Procedure

The transcript of each interview was analysed separately in the order presented in the Results section; Muslim women, Muslim men, white English women, white English men. Each transcript was divided into meaning units (MU) defined as portions of text describing, as far as possible, one phenomenon. Each MU relevant to understanding the meaning of organ donation was assigned at least one code descriptive of its content. Categorisation was conducted iteratively whereby initial codes were developed from the data but then refined as more data was analysed. Increasingly, more MUs were assigned codes already devised. After each transcript had been analysed, the content of each code was scrutinised to ensure that it described adequately the MUs it contained. At this point some codes were re-named and/or merged. Once code titles and content were stabilised, memos written throughout the analysis were used to help cluster codes hierarchically at an increasing level of abstraction (from codes to higher-order categories to themes) to form a micro-model for each of the groups. A core category, common to all four groups which brought together the analysis at the highest level of abstraction took the form of a question; 'Is there a cost to organ donation?'

Credibility Checks

An 'auditor' evaluated the fit between a sample of code titles and content. This was conducted by a female postgraduate with experience in qualitative research. Two

quotes from each of five codes were selected from each micro-model. Agreement was high with the auditor placing 39 of the 40 quotes in the same code as had the original researcher. To gain additional viewpoints, two participant representatives were recruited for each of the four groups; two by word-of-mouth and six who had been willing but unable to attend their original focus group meeting. Generally, each micro-model was well received although, as expected, not all respondents agreed with every aspect and some minor clarifications were obtained.

RESULTS

We describe the higher-order categories and themes that were developed into a micro-model of the data for each group which, together, elucidate the core category: 'Is there a cost to organ donation?'. The pseudonym in brackets indicates the participant from whom the quote is taken or who expressed the idea described.

Muslim Women of Pakistani Origin

Theme 1: Costs and benefits

In considering the 'benefits of organ donation', it was thought good for individuals and to have wider positive repercussions; "*it's much better for the whole family as a whole having the kidney transplant*" (Nafeesa). The Muslim women also discussed the 'context and consequences of receiving organs'. Deciding to receive an organ was seen as most likely due to desperation. However, for some, an over-riding consideration was to follow the rules of Islam. There was concern that a person had to die to allow another to live, with one woman questioning at what point organs were removed; "*they can't let you die before they take the, your organs out can they?*" (Nafeesa). There was also debate about whether receiving an organ was selfish and might lead one away from God.

Concerning 'issues involved in giving organs', the women debated Islam's stance on remaining intact after death and worried about being cut-up. There were indications that just being reminded of death may put people off; *"X gave me that form and I read it I thought ugh [...] I'd rather not go there at the moment (I: What kinds of thought did it bring up? What kind of worries?) Just the death you know"* (Taseen).

----figure 1 about here----

Theme 2: Beliefs, rules and understandings mediate relationship with God

'Evidence and authority' captured the way in which their religious code was central to the Muslim women's decisions about giving or receiving organs. However, they disagreed as to whether Islam had a single standpoint. Fozia drew on the evidence of sacred texts, Fozia and Taseen cited husbands, Sabina suggested the knowledge of a Bedayr (elder), and Fozia and Nafeesa suggested people able to read Arabic. However, Sabina also suggested a more individual aspect; *"I think a lot of it is to do with religion and a lot is their own personal feelings"*.

Islam's stance on the 'intactness of the body in the after-life' was important to the Muslim women and their relationship with God. However, issues were debated about the difficulty remaining intact in some instances; *"Well if you car crash you'll be totally you know (burnt) ... yes burnt, mangled, how do they go back to God?"* (Nafeesa). However, Sabina viewed the body and soul to be separate; *"when we die it's not our body that goes, it's our soul that goes"*.

Comments under 'beliefs about a natural order' implied shared rules or understandings. Many felt that animal organs would be unacceptable, with unanimous agreed that pig organs would be unacceptable. Although Taseen considered that; *"If it was a sheep's (organ) I would"*, most viewed animals as categorically distinct from

humans. Some preferred to have an organ from a person of the same religion, but this was not universal. Finally, accepting death appeared to be important and it is possible that organ donation may be seen by some as challenging fate.

Theme 3: Sense of self

In the 'meaning of specific body parts', biological ideas of the heart were mentioned as well as beliefs that the heart contains feelings, which may be influenced by everyday sayings; *"like you say we know the person but we don't know what is inside their heart. So it is like saying you know the heart does refer (to feelings)"* (Fozia). This added to concerns that the donor's personality may be transplanted with their organ. Being able to see the eyes appeared to create an attachment to them which could make people more reticent to donate. Attractiveness was also an important aspect of the eyes and may have particular significance for Muslim women; *"if somebody's veiled up, covered up it's the eyes that'll be there isn't it? It makes you look"* (Fozia). However, some mentioned that eyes and hearts should be no more special than other body parts.

The women also discussed 'issues of choice and control regarding bodily rights' and highlighted possible tensions between their own wishes and the beliefs of their family or culture. For example, Zakia related how her decision to carry a donor card changed; *"I carried it for two years, me and my brother and um I found out they said it isn't allowed in Islam and stuff and someone told us to get rid of it"*. However, others emphasised personal choice in their decision about card carrying.

Muslim Men of Pakistani Origin

Theme 1: Perceived code of conduct for living as a Muslim

The Muslim men were concerned about 'meddling with the natural or God-given order' although it was thought that religious beliefs might be overlooked in life-

threatening situations. However, many found xenotransplantation abhorrent; "*I think when it comes to pig organ any Muslim would prefer to die*" (Mubashar). This was related to religion; "*our prophet Mohammed, he said not to eat this (pig) meat*" (Tariq) but also to a categorical distinction between human and animal. However, it was thought that the organs from some animals might be acceptable; "*a lot of 'em people would agree – agree with sheep's*" (Zaber). Most were reticent about donating organs across race or religion although some thought they might change their mind if a life was at stake.

----figure 2 about here----

Regarding the 'perceived clarity of Islam's rules', many regarded organ donation a complex issue partly because it is not covered in the Koran and there was debate about how holy writings might be interpreted to clarify Islam's stance. The men considered it important to have a guide and Tariq cited the writings of Mohammed; "*our prophet put a restriction here (...) restrictions to accept any other non-Muslim's you know any part of body*". Older adults were thought likely to be clear about Islam's stance and, although their views on donation were perceived as "*completely different*" (Sakib) from those of younger people, Zaber felt that "*there might be, you might some old people really into it*".

There was concern about the 'treatment of the dead body'. Mubashar explained that, for some, intactness of the body is important for the next life and this was echoed by Zaber; "*so long as he's got his heart (after death)*". However, Mubashar's own belief as a Muslim was that "*the soul goes to a different world and it exists, but the body is going to get into mud*". For some, the delays in UK burials, legal requirements, and medical practices were viewed as placing the dignity of the body and sanctity of the funeral in jeopardy. Mubashar explained that the dignity of a

women's body is particularly important and he raised concerns about interference from doctors; "*the family will really try hard to avoid any post-mortem, so they can protect the dead body from interference*".

Theme 2: Social effects of organ donation

Under 'altruism issues', many considered saving life an extremely worthy goal and the act of donation was seen as having social benefits through the continuing contribution of the person who is saved. It was also considered that the altruistic act of one person could encourage others; "*if you're giving it to your own family that will encourage others as well to give their organs to somebody in their own family*" (Amran). However, costs were also considered; "*If it's (...) kidneys then obviously then it matters when you are alive, then you think twice why should or shouldn't*" (Zaber).

In live donation, emphasis was placed on 'family issues' and the men discussed potential problems between relatives; "*you know a kidney to brothers and sometime I say oh no what you doing? And you have to take caution also that's the problem create - you know - in family*" (Sakib). Even so, donation was considered less acceptable beyond the family, even when the deceased had expressed the desire. Mubashar felt it unlikely that parents would donate their child's organs as "*They wouldn't risk further grief*", although this view was not unanimous.

Very little was offered regarding eye donation but two mentioned potentially negative consequences for the family. It may prevent someone looking good for mourners or cause distress through seeing somebody who has a loved one's eyes. The men subscribed to a biological view of the heart, although it was considered that other people may worry that a donated heart contains contaminating aspects of the donor's personality, e.g., that "*when it goes in there will it be the same and will it be thinking*

the same" (Zaber). However, eye and heart donation did not appear to have special meaning for these Muslim men.

White English Women

Theme 1: Sense of self

In 'beliefs about the nature of the self after death', intactness of the body was considered important by some. However, many believed the spirit or soul to be distinct from the body and Karin situated this within her religious beliefs; "*As a Christian I would agree with that (...) because your body's left behind*".

----figure 3 about here----

Participants were concerned with the question 'does the 'self' have a specific location in the body?'. Eyes were particularly important as "*You tend to feel yourself focused there*" (Maria) and were linked to person's soul or personality. A variety of beliefs were expressed about the heart; "*I don't think they (feelings) come from your heart.*" (Laura), with some leading to reservations about receiving and donating; "*I don't want to give my heart and my eyes because I feel like you think things with your heart*" (Jane).

In 'respect for the dead person', women were concerned about dignity of the body and some emphasised the appearance of the dead, particularly for relatives. However, having one's own wishes met was also considered important; "*I wouldn't want somebody at the end of the day to come up and say 'no I don't want it doing*" (Sara). Some expressed concern about a sense of 'difference and contamination'; "*it's the thought of having somebody else's bits inside me.*" (Emma), and indicated preference for a cloned organ or one from a relative. There were also worries about giving or receiving a defective organ.

Theme 2: Issues of control over distal systems

‘Clarity and trust in organ donation system’ brought together several worries. How clear is the boundary between life and death?; "*are you sure you're not dead?*" (Amy). Are there negative implications for being in a coma?; "*They might not try as hard to keep me going*" (Sara). To what use are organs put?; "*the treatment of others*' - *what exactly are you going to pin that one down*" (Maria). Hence, there were concerns about the trustworthiness of the donation system which were often linked to organ shortages.

In ‘tensions between scientific advances and ethical issues’, views were expressed about animal organs. Emily "*would be appalled if they were killing animals just to give their organs*" although this would not be an issue for Amy if the animals were "*specially bred for that purpose*". For some, the issue was lack of consent, or that "*it's cruel*" (Emma). However, many thought that if their child was in danger such concerns could be waived. They worried about scientific advances including cloning. However, Sara suggested that "*it's God that's given somebody the idea to think this (cloning) up*" and Maria argued that it could offer benefits; "*the most ethical is to be able to grow it, where you are not killing anybody or anything*".

Theme 3: Family issues

In ‘family issues in live donation’, women felt that being a relative would override their fears, particularly with regard to children, although they also mentioned drawbacks such as "*there could be a lot of pressure put on - er - siblings*" (Anne).

Many considered that donation decisions were ‘made within an emotional context’ and that indicating one's wishes was important "*when it comes to taking the emotive onus away from your relatives*" (Karin). Media influences were positive; "*she went on to live then you do - you feel really good and that made me think maybe I should carry a card*" (Emily), but also negative, such as in some films; "*The fact that*

different bits they've changed their personality" (Laura). However, although it is "*not something you think about every day?"* (Jane), many felt if their survival was in jeopardy they would be desperate and "*just want to stay alive"* (Emily).

White English Men

Theme 1: Meaning of the body

For some men, the 'body was imbued with personal meaning' so donation was considered "*one of the most personal gifts you can give"* (Jack). However, many maintained a sense of ownership of their body after death and debated their right to make conditions; "*would you give your or-organs to somebody who had completely run their body into the ground?"* (Simon). Children's bodies held particular significance for fathers who were reticent to have their child "*cut up (...) even if he were dead"* (Peter), although Alex had "*to think – well if gonna save another child's life?"*".

----figure 4 about here----

There were 'special meanings of certain organs'. Martin considered eyes particularly important as "*they're impregnated with your memories"* and represent a person's individuality. For Jim, the significance was that "*You can actually see your own eyes"*. This may make people feel squeamish or, on the other hand, encourage donation as "*it's much easier to imagine not being able to see"* (Jim). Metaphors may influence some men's beliefs; "*I knew someone who didn't like – wouldn't like their eyes donated (...) windows on the soul I think was the theory behind that one"* (Simon), although most offered science-based opinions. A few thought others might associate the heart with feelings, but none considered the heart special.

Many viewed the 'body as an object' and the cadaver a commodity to be used like "*a lot of waste meat"* (Allan), although some were concerned about exploitation

by the rich or National Health Service (NHS). They also worried about animal rights although acknowledged that "*animals are farmed for the table*" (Fred).

Theme 2: Issues of choice, control, power and authority

Many of these men had a 'distrust of the medical system'. This related to the NHS having sold blood and removed cadaver organs without consent. Moreover, within the context of organ shortages, some feared that carrying a donor card might influence doctor's decisions; "*are they going to turn you off because now they know they can use your organs?*" (Simon). Others were concerned about the way information may be organised in the NHS; "*there's a card there but there's no real central register*" (Jim).

Some had 'concerns about choices being constrained'. The fairness of the donation system was deemed variable; "*depend on which hospital you going to*" (Jim) and there was uncertainty about eligibility; "*I wouldn't like to think that because I'd liked a drink since I was 16 or 17 (...) that someone's going to turn around and say no well you were a drinker*" (Fred). Martin worried that religious beliefs or ethnicity may created inequities; "*you're going to get the same people putting into the system all the time*". This view was not widely held, although there was concern that "*they (Jehovah's witnesses) made choices for the children*" (Simon).

Discussion was had regarding 'issues of survival in making choices about organ donation'. Most thought the desire to survive would likely over-ride other considerations, such as reservations about the acceptability of animal organs. However, imminent death may provoke a backlash with regard to donating one's organs: "*you're laid there on your death bed and someone says will you donate your organ? I think your instinct then becomes no I won't (...) I want to survive*" (Jack).

There were considered to be ‘tensions and ethical issues in making decisions about organ donation in relation to other people’, particularly loved ones. In cadaver donation, relatives might feel pressurised to agree because of time constraints or be confused in the emotional turmoil and *"be tempted to say no"* (Jack). Making decisions about live donation involved the strength of the relationship; *"I wouldn't even consider giving it to other than – other than family or very, very close friend"* (Fred), and this had to be balanced against; *"putting yourself as much at risk"* (Jim). Some considered that the parent should make the relevant choice for their child and several mentioned trying to spare their wife; *"I've said look - er - my decision is this - so you in effect - you've made the decision for her"* (Jim).

A summary of results is presented in table 2 which captures the main differences and similarities between the groups.

----table 2 about here----

DISCUSSION

The main finding of this study is that, for potential donors, the act of organ donation can be perceived as involving a personal cost. This cost can be associated with religious belief, the ethics of the organ donation service, and scientific advances, as well as the meaning of the body and of specific body parts. Moreover, people, especially some women, can be worried that having a transplant may affect them in negative ways related to disease or personality change. In addition, in spite of a Fatwa stating that the giving and receiving of organs is compatible with Islam, many Muslims appear to be unsure if organ donation is allowed (see also Ahmed et al., 1999; Randhawa, 1998; Sheikh & Dhimi, 2000). In the following paragraphs we discuss our findings in relation to our research aim of exploring the meanings of

organ donation, comparing people across gender and across two ethnic groups, with particular emphasis on donation of the heart and eyes.

One of the main differences between the Muslim and white English groups was the influence of religious belief. For Muslims there was a strong emphasis on understanding Islam's position on organ donation. Cronen and Pearce (1985) suggest that there are different levels of meaning which influence people's beliefs at any one time, the most important being that person's 'highest context'. For many Muslims, feeling confident that they are behaving in accordance with Islam may be their highest context in organ donation. However, as Cronen and Pearce explain, the highest context is not always stable and there were indications in our findings that, in particular, many Muslim women's highest context may change, for example, when a family member is at risk. The influence of religious belief for Muslims on organ donation is supported by the literature (e.g., Sheikh & Dhami, 2000), although, as indicated in our Introduction, it is still unclear if knowledge about organ donation may have an even greater effect on behaviour. However, our study does not uphold Sanner's (1994) hypothesis that only people with negative beliefs about organ donation refer to their faith, as some Muslims made reference to Islam while being positive about donation. So, in perhaps making assumptions about what Muslims believe, the transplant co-ordinators may miss some valuable donors (TCA, 1995).

With further reference to religious belief, many Muslims raised concerns about material intactness and there was debate as to whether the body returned to Allah physically or metaphysically. Although intactness was an issue for the white English women, it was not strongly linked to religion. For the Muslim men, Islamic burial traditions were also particularly important and Gatrad's (1994) commentary on Islamic customs confirms our findings regarding the importance of procedures such as

rapid burial. Harré's (1991) work may help our understanding of such issues in relation to organ donation in that he suggests that rules for the proper disposal of the body have been devised to respect the person-hood of the deceased. However, Sheikh and Gatrad (2000) also draw attention to the way that Muslim death rites (washing, shrouding, burying) may provide stability for relatives. Hence, for many Muslims at least, the procedures associated with cadaver donation entail a cost in potentially disrupting their honouring of the dead and experience of bereavement. The Muslim Counsel of Britain (2000) "is keen to promote a better appreciation of the needs of Muslim patients" (p.1) and amongst its activities has launched a book aimed at informing the medical services about such issues (see Sheikh & Gatrad, 2000).

Xenotransplantation also raised different issues for the two ethnic groups. Some white English were in favour of using animal organs. Others were less enthusiastic but felt that the desire for self-preservation and for the well-being of children may override this (see also Lundin & Widner, 2000). However, our most pertinent finding was that, whereas the concerns of the white English revolved around animal rights, the Muslims viewed xenotransplantation unfavourably in terms of animals and humans being essentially different. Hence, although we must be careful not to over-stress this possible ethnic difference, advances in science could pose different ethical problems for different communities in ways which we have hardly begun to understand.

Another ethnic difference was that the white English expressed a lack of trust in the medical profession and some feared that if they carried a donor card doctors might not try so hard to save their life. Such fears have also been noted by North American authors (e.g., Cortlett, 1985; Prottas, 1983). Members of our Muslim groups did not voice similar concerns and this may have been an artefact of the

specific participants who took part. On the other hand, the primary issue of whether or not organ donation is allowed in Islam might eclipse the fear that carrying a card may impact negatively on medical care. Moreover, Muslims may, generally, have more confidence in medical staff than some other ethnic groups and anecdotal evidence suggests that this may be the case (Ahmed, 2000, personal communication). Further still, the specific areas of concern may just be different for different groups. For example, some Muslims mentioned worries about post-mortem operations interfering with their customs.

Beliefs about the ‘fairness’ and ‘equity’ of the organ donation system were of considerable importance to some white English men, whereas this was not such an issue for the other groups. This finding seems to be novel although, given our small sample sizes, we must be tentative about this difference being generic. Many white English men considered it important to be able to choose to whom they gave their organs and that they should be treated fairly if they, themselves, needed an organ. In writing about Gilligan’s work, (e.g., 1977), Lott (1990) suggests that men and women have different views of fairness and justice. Men are more likely to define justice abstractly ‘by the balancing of individual and competitive rights’ (p. 68) whereas, for women, moral issues often stem from relational concerns. Certainly, the white English men were pre-occupied by issues of individual fairness whereas members of the other groups were more concerned about moral issues in relation to their family. Moreover, some white English men associated fairness in the organ donation system with having rights over one’s body. This concurs with Saltonstall’s (1993) study which found that men are more likely to view their bodies as objects belonging to them in contrast to women who often refer to their body as having a subjectivity of its own.

However, this does not explain why the Muslim men did not react in the same way as the white English men. It is possible, as the highest context for many Muslims is likely to be Islam, other concerns have much less immediacy. Another explanation is that control may manifest differently in different cultures. Weiz, Rothbaum and Blackburn (1984) suggest that control can take two major forms. Primary control relates to influencing other people and circumstances, whereas secondary control is about accommodating to existing realities. Primary control is more evident in Western cultures while secondary control is more prominent in the East, particularly in traditional Japanese culture. It is possible to understand the Muslims as demonstrating aspects of secondary control, particularly as Weiz et al. (1984) suggest that religion places an emphasis on secondary control and that Dickinson and Bhatt (1994) found that people of South Asian origin display elements of fatalism in their health beliefs. Although this explanation helps makes sense of our findings, we must avoid over-analysing the findings from such a small group. Moreover, the Muslim women also showed aspects of primary control in, for example, their concern about having the right to dispose of their bodies as they wished.

There were gender differences in the way that the heart was spoken about in that women were more likely to attribute to it aspects of personality and emotion. This is consistent with research suggesting that women are more likely to express emotions than are men (Fischer, 1998) and feel happier doing so (Saurer & Eisler, 1990). In talking about the heart, men took a scientific perspective and used primarily a machine metaphor. This is in keeping with research suggesting that men's talk centres around rational and dispassionate themes (Gough, 1998). Belk (1987; 1990; Belk & Austin, 1986) suggests that the more meaningful an organ is, the less willing people are to donate it. This is supported by Wilms et al. (1987) who found that women were

approximately half as likely to donate the heart as were men, with explanations for non-donation in terms of people's images of the organ as more sacred, emotional, mysterious, and less understandable than the images held by donors. However, most of the concerns expressed by our female participants were in term of receiving rather than of donating the heart. Their fear of personality change associated with organ donation has already been documented (Basch, 1973; Castelnuovo-Tedesco, 1973) and has an interesting link with ancient beliefs. For example, Harré (1991) suggests that holy relics provide evidence that the body and its parts have been understood in the past to embody moral qualities.

There was less difference in the meaning of the eyes than of the heart between groups. This has an interesting parallel with Wilms et al. (1987) who found a larger difference between men and women's willingness to donate hearts than eyes. Our findings concord with and expand those of Kent and Owens (1995) who report that people's disinclination to donate corneas may be linked to the visibility of eyes and the presence or absence of beliefs about the eye embodying a person's character. We found that eyes and sight were associated with identity in a multitude of ways including sense of agency, awareness, and memory. Participants from three of the groups (not the Muslim men) also commented on the fact that eyes are external and can be seen, with participants in both of the women's groups having a preference for donating internal organs (see also Sanner, 1994). Many of the Muslim men and white English women thought that the whole eye is donated and their concerns related, in part, to the belief that eyes are distinctive for each individual and are linked to identity. It could be that for some Muslim women, eyes hold a particularly strong link with their sense of self because of the wearing of veils and this would be an interesting line of enquiry to pursue.

A fascinating aspect of our participants' discussion around the meaning of the heart and eyes was the issue of reification. Reification occurs when, through the use of metaphor, imagery, or other shared linguistic resource people come to treat what is an issue of language as something 'real' (Potter & Wetherell, 1987). For example, some participants seemed to believe that because hearts are metaphorically related to feelings, as in poetry, hearts literally are feelings or contain feelings. In the case of eyes, one participant in each white English group appeared to believe that, because eyes are talked about as being a 'window on the soul', they in fact reflect the soul. However, eyes were reified to a much lesser degree than were hearts, perhaps as there is less imagery associated with eyes in everyday language. Such reification seems likely to have implications for organ donation. Indeed, Belk (1990) has suggested that people who associated the body with the self will be less likely to donate body parts than those who think about the body in terms of a garden (which can be harvested), or as a machine (which has replaceable parts).

There were also differences between gender groups regarding concerns about the transmission of disease through donation and limits to the life-span of a transplanted organ. Such issues have not been highlighted previously, although studies have pointed to vaguer concerns about to whom organs had belonged (e.g., Basch, 1973). Although the average man's life expectancy is less than the average women's (Helgeson, 1995), and men are more likely to die of heart disease (Verbrugge, 1980), none of the men were concerned about contracting a disease from a donated organ. This gender difference may relate to the fact that men are, in general, less concerned about health issues than are women (Wardle & Steptoe, 1993). Men's attitudes to health can also be considered from a social support perspective in that they are less likely to seek help (Butler, Giordano & Neren, 1985), possibly because

this implies weakness and gender role expectations teach men not to admit vulnerabilities (Helgeson, 1995). Hence, it may be that many men would not wish to discuss some issues surrounding health, particularly in an all-male group, and/or that this is simply not in their repertoire.

While qualitative research does not attempt to approximate quantitative methodologies with regard to generalisation, it is still important to recognise the limits of our study. Due to recruitment difficulties, half the white English men were firemen. It is not clear what impact, if any, this had on our findings but possibly represents a bias in our research. However, even though fire-fighting is one of the helping professions, the findings from the white English men were some of the least altruistic and central aspects of their discussions reflected features of male perspectives well substantiated by research. Our sample sizes are small so that we cannot be sure that the differences we found between groups are robust. However, our aim was to explore the meanings of organ donation in order to begin to understand the possible impact of ethnicity and gender and have highlighted where our findings are novel, and so warrant further investigation, and where they are supported by past literature. Finally, it is possible that focus group interviews may have led to social pressure to converge opinion, however differences between group members were evident.

Given that this study only included people aged 27 to 50, it might be fruitful to investigate if the meanings of organ donation vary with life-stage. It would also be interesting to explore the relationship between reification of imagery associated with specific body parts and decisions to restrict donated organs. Finally, although the UKTSSA have produced culturally sensitive leaflets and posters targeted at British Asians, more research is required on the informational needs of the Muslim

community about organ donation and, in particular, how best to disseminate knowledge of the 1995 Fatwa. This may be important as Sheikh and Gatrad (2000) are of the opinion that “this ruling will have widespread appeal particularly among second- and third-generation British Muslims” (p.107).

In conclusion, in relation to organ donation, one cannot simply view people as rational beings. One must understand that people are embodied beings whose sense of self is entwined with having and being a body, that concerns related to embodiment are often generated in metaphorical language, and that gender and ethnicity have an influence on the meaning of embodiment. However, this study also demonstrates that organ donation is more than just about the body. The issue that we found to integrate our findings at the highest level of abstraction was that of weighing the costs and benefits of organ donation. This was related to religious considerations and family concerns as well as moral judgement of scientific and medical conduct.

ACKNOWLEDGEMENTS

We are very grateful to our participants for taking the time to provide us with such rich material. We would also like to thank Mushtaq and Shenaz Ahmed for their help recruiting participants and advising us about Muslim culture, and Janet McCarthy for her help in conducting the credibility check. Correspondence concerning this article should be addressed to Clare Hayward, Academic Unit of Psychiatry, 15 Hyde Terrace, University of Leeds, Leeds, LS2 9JT, UK.

REFERENCES

- Ahmed, W. Harris, S. Brown, E. (1999). Attitudes to organ donation among South Asians in an English high street. *Journal of the Royal Society of Medicine* 92, 626-627.
- Anwar, M. (2000). Muslims in Britain: Demographic and socio-economic position. In: A. Sheikh & A.R. Gatrads. *Caring for Muslim patients* (pp.3-15). London: Radcliffe Medical Press.
- Bartucci, M.R. Bishop, P.R. (1987). The meaning of organ donation to families. *ANNA Journal* 15, 369-371.
- Basch, S.H. (1973). The intrapsychic integration of a new organ. *Psychoanalytic Quarterly* 42, 364-384.
- Batten, H. (1992). The social construction of altruism in organ donation. In: J. Shanteau & R. Harris. *Organ donation and transplantation: Psychological and behavioral factors* (pp. 83-96). Washington, DC, USA: APA.
- Belk, R.W. (1987). Identity and the relevance of market, personal and community objects. In: J. Umiker-Sebeok. *Marketing and semiotics: New directions in the study of signs for sale*. NY, USA: Mouton de Gruyter.
- Belk, R.W. (1990). Me and thee versus mine and thine: How perceptions of the body influence organ donation and transplantation. In: J. Shanteau & R. Harris. *Organ donation and transplantation: Psychological and behavioral factors* (pp. 139-149). Washington, DC, USA: APA.
- Belk, R.W. Austin, M.C. (1986). Organ donation willingness as a function of extended self and materialism. In: M. Venkatesen. *Advances in health care research*. Washington, DC, USA: Association for Health Care Research.

- Berg, B. L. (2001). *Qualitative research methods for the social sciences* 4th ed.
London: Allyn and Bacon.
- Black, D. Townsend, P. Davidson, N. Whitehead, M. (1988). *Inequalities in health: The Black report: The health divide*. Report of the Working Group on Inequalities in Health, London: HMSO.
- Butler, T. Giordano, S. Neren, S. (1985). Gender and sex-role attributes as predictors of utilisation of natural support systems during personal stress events. *Sex Roles* 13, 515-524.
- Carlisle, D. (1995). Life-giving Fatwa. *Nursing Times* 91, 14-15.
- Castelnuovo-Tedesco, P. (1973). Organ transplant, body image, psychosis. *Psychoanalytic Quarterly* 42, 344-363.
- Corlett, S. (1985). Public attitudes toward human donation. *Transplantation Proceedings* 17, 103-110.
- Cronen V.E. Pearce, W.B. (1985). Toward an explanation of how the Milan method works: An invitation to a systemic epistemology and the evolution of family systems. In: D. Campbell & R. Draper. *Applications of systemic family therapy: The Milan approach*. London: Grune and Stratton.
- Derege, S. Bartucci, M.R. (1999). Issues surrounding xenotransplantation. *AORN Journal* 70, 428-32.
- Dickinson, R. Bhatt, A. (1994). Ethnicity, health and control: Results from an exploratory study of ethnic communities' attitudes to health. *Health Education Journal* 53, 421-29.
- Exley, C. Sim, J. Reid, N. Jackson, S. West, N. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: A pilot study. *Social Science & Medicine* 43, 23-28.

- Fischer, A. (1998). Emotion. In: K. Trew & J. Kremer. *Gender and psychology* (pp. 82-94). London: Arnold.
- Fulton, J. Fulton, R. Simmons, R. (1977). The cadaver donor and the gift of life. In: R. G. Simmons, S. D. Klein & R. L. Simmons. *Gift of life: The social and psychological impact of organ donation* (pp. 338-376). London: Wiley.
- Gatrad, A.R. (1994). Muslim customs surrounding death, bereavement, post-mortem examinations and organ transplants. *British Medical Journal* 309, 20-27.
- Gilligan, C. (1977). In a different voice: Women's conceptions of self and morality. *Harvard Educational Review* 47, 481-517.
- Glaser, B.G. Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Gough, B. (1998). Roles and discourses. In: K. Trew & J. Kremer. *Gender and psychology* (pp. 15-26). London: Arnold.
- Harré, R. (1991). *Physical being*. London: Blackwell.
- Helgeson, V. (1995). Masculinity, men's roles, and coronary heart disease. In: D. Sabo & D.F. Gordon. *Men's health and illness: Gender power and the body* (pp. 68-104). London: Sage.
- Kent, B. Owens, R. (1995). Conflicting attitudes to corneal and organ donation: A study of nurses' attitudes to organ donation. *International Journal of Nursing Studies* 32, 484-492.
- Kopfman, J.E. Smith, S.W. (1996). Understanding the audiences of a health communication campaign: A discriminant analysis of potential organ donors based on intent to donate. *Journal of Applied Communications Research* 24, 33-49.

- Lott, B. (1990). Dual natures or learned behavior: The challenge to feminist psychology. In: R.T. Hare-Mustin & J. Marecek. *Making a difference: Psychology and the construction of gender* (pp. 65-101). New Haven: Yale University Press.
- Lundin, S. Widner, H. (2000). Patients' attitudes to xenotransplantation: 'I'll do anything not to die'. *Lakartidningen* 16, 1940-1943.
- Muslim Counsel of Britain (2000) <http://www.mcb.org.uk/news180700.html>
- New, B. Solomon, M. Dingwall, R. McHale, J. (1994). *A question of give and take*. London: King's Fund Institute.
- Potter, J. Wetherell, M. (1987). *Discourse and social psychology*. London: Sage.
- Prottas, J. (1983). Encouraging altruism: Public attitudes and the marketing of organ donation. *Health and Society* 61, 278-306.
- Randhawa, G. (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology: Dialysis Transplantation* 13, 1949- 1954.
- Roderick, P.J. Raleigh, V. S. McGowan, M. Mallick, N. (1994). Population need for renal replacement therapy in Thames regions: Ethnic dimension. *British Medical Journal* 309, 1111-1114.
- Saltonstall, R. (1993). Healthy bodies, social bodies: Men's and women's concepts and practices of health in everyday life. *Social Science & Medicine* 36, 7-14.
- Sanner, M. (1994). Attitudes toward organ donation and transplantation: A model for understanding reactions to medical procedures after death. *Social Science & Medicine* 38, 1141-1152.
- Saurer, M.K. Eisler, R.M. (1990). The role of masculine gender role stress in expressivity and social support network factors. *Sex Roles* 23, 261-271.

- Shanteau, J. Harris, R. (1992). Why psychological research on organ donation? In: J. Shanteau & R. Harris. *Organ donation and transplantation: Psychological and behavioral factors* (pp. 1-7). Washington, DC, USA: APA.
- Sheikh, A. Dhami, S. (2000). Attitudes to organ donation among South Asians in the UK. *Royal Society of Medicine* 93, 161-162.
- Sheikh, A. Gatrad, A. R. (2000). Death and bereavement: An exploration and a meditation. In: A. Sheikh & A. R. Gatrad. *Caring for Muslim patients*. London: Radcliffe Medical Press.
- Sque, M. Payne, S. A. (1996). Dissonant loss: The experiences of donor relatives. *Social Science & Medicine* 43, 1359-1370.
- Transplant Co-ordinators Association (1995). *Relative's refusal of organ donation*. UK: Department of Health.
- UK Transplant Support Service Authority (1999). *Transplant activity 1998*. UKTSSA
- Verbrugge, L.M. (1980). Sex differences in complaints and diagnoses. *Journal of Behavioral Medicine* 3, 327-355.
- Wardle, J. Steptoe, A. (1993). The European health and behaviour survey: Rationale, methods and initial results from the United Kingdom. *Social Science & Medicine* 33, 925-36.
- Weisz, J.R. Rothbaum, F.M. Blackburn, T.C. (1984). Standing out and standing in: The psychology of control in America and Japan. *American Psychologist* 39, 955-969.
- Wilms, G. Kiefer, S.W. Shanteau, J. McIntyre, P. (1987). Knowledge and image of body organs: Impact on willingness to donate. *Advances in Consumer Research* 14, 338-341.

		White		White	
		Muslim	English	Muslim	English
		women (5)	women (9)	men (5)	men (8)
Occupational class	I	1	1	0	0
	II	2	4	2	3
	III	2	4	2	5
	IV	0	0	1	0
Leeds-Bradford	6-10yrs	0	0	1	0
	11-15yrs	0	0	0	2
	16-20yrs	0	0	1	0
	21+yrs	2	3	3	0
	life	3	6	0	6
Religion	Muslim	5	0	5	0
	Church of England	0	4	0	2
	Mormon	0	1	0	0
	Greek Orthodox	0	1	0	0
	Catholic	0	0	0	2
	Methodist	0	0	0	1
	None	0	3	0	3

Table 1: Participants' occupational class, length of residence in Leeds-Bradford, and religion

	Muslim women	White English women	Muslim men	White English men
Hearts as meaningful	✓	✓		
Personality change	✓	✓		
Eyes as meaningful	✓	✓		✓
Reification of body parts	✓	✓		
Concern about health of the organ	✓	✓		
Religious concerns	✓		✓	
Meddling with nature/God's creation	✓	✓	✓	
Family concerns	✓	✓	✓	
Contamination from animals	✓		✓	
Animal rights		✓		✓
Distrust of the medical system/control		✓		✓
Issues of fairness in donation system				✓

Table 2: Comparisons between ethnic and gender groups