

A Cross Sectional Study To Investigate Reasons For Low Organ Donor Rates Amongst Muslims In Birmingham

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Abstract

Background: The lack of organs in the UK has prompted large-scale debates in recent times. One of the problems has been the lack of organ donors from ethnic backgrounds. Our study is a cross-sectional study of the Muslim population of Birmingham. It explores the opinions of Muslims towards organ donation in light of their religious beliefs.

Methods : A questionnaire was produced with the help of the organ donor coordination team in Birmingham. The questionnaires were filled by interview of Muslims who were found attending the local gyms, university and from the local neighborhoods.

Results : This study found that in spite of their willingness to accept organs in end organ failure, Muslims are apprehensive in showing their willingness to donate. This is partly due to a split in the scholarly opinions on the matter across the Muslim world, and partly due to lack of knowledge and discussion within the community.

Conclusions : The shortage of organ donors in the UK is a worrying problem, but one that needs to be dealt with sensitivity towards the beliefs of the various groups which contribute to our ethical make up. More work needs to be done to propagate the opinion of those Islamic scholars who are in favor of organ donation.

This work was carried out in Birmingham University, UK in 2004.

BACKGROUND

Over 5000 people are waiting for an organ transplant that will either save or dramatically improve their lives¹. Currently the demand for transplant organs far outstrips the supply in the UK². Many people die each year because of the lack of available organs. Currently an organ card system exists in the UK, in which individuals opt to be put on an organ donor register. Much debate has been raging recently on the merits of changing this to an opting out system. This would involve individuals actively opting not to be put on the register. In essence this system holds that anyone not clearly and openly declaring their opposition to their organs being used after their death has no objections to becoming an organ donor. This understanding of “presumed consent” has recently been debated in parliament and has had the backing of doctors.

Within the larger scheme of the problem of organ shortages, there lie far more acute and specific problems. One of these

problems is the issue of a shortage of donors from the ethnic minorities. Asians, for example, have been shown to be disproportionately over represented on transplant waiting lists in some regions of the UK². However, a brief discussion with the Organ Donor Co-ordination Team in Birmingham revealed that very few Asians were on the list of organ donors. This not only adds to the problem of organ shortages but also has a greater medical implication in that it has been proven that tissue type compatibility and blood group matching is more difficult across racial groups^{2,5}. In order to alleviate these difficulties the Birmingham Organ Co-ordination Team began liaising with the UK Muslim Council in 1995 to address this matter. It subsequently became heavily involved in the issuing of a ruling, fatwa, by the UK Muslim Law council³ regarding the permissibility of organ donation. The council resolved, amongst other things, that

1. The council accepted brain stem death as constituting the end of life
2. The council supported organ transplantation as a means of alleviating pain or saving life

3. Muslims were permitted to carry donor cards.

The facet of Islamic law that the council used to justify the above ruling was the Islamic legal maxim *al-darurat tubih al-mahzurat* or “necessities overrule prohibition”. Using this maxim they argued that the ruling regarding prohibition of delaying burial could be overruled if the delay was necessitated in order to save a life. In Islamic tradition preserving life is a fundamental function of Shariah, Islamic Law, and the act of saving a life is greatly rewarded by God, Allah. The Council's ruling relied on the fact that as organ donation clearly saved lives it was hence permissible. Other Islamic authorities to have backed organ donation as being permissible include The Shariah Academy of the Organization of Islamic Conference, the Grand Ulema Council of Saudi Arabia, the Iranian Religious Authority and the Al-Azhar Academy of Egypt

The issuing of these fatwas was considered a success and a step forward and it was hoped it would lead to a breakthrough in resolving the problem of low donor rates amongst Muslims. Sadly, nine years since these developments, the anticipated impact has not been realized; organ donation in Muslim communities has not increased. This study aims to look at the barriers that exist that are preventing the increase in a willingness amongst Muslims to donate their organs.

LITERATURE REVIEW

Not many studies were found which concentrated solely on Muslims. Following is a review of the literature found.

In an exploratory study by Randhawa², 64 Asians were interviewed in Luton regarding their opinions towards organ donation. Of the 32 Muslims interviewed, only 2 were aware of any Islamic fatwas regarding organ donation. Also only 2 Muslims were of the opinion Islam regards organ donation favourably.

In a study by Sheikh et al⁶, 25 Muslims were interviewed by questionnaire. They found that 12 were unwilling to donate after death whereas a further 10 were unsure. Hence, this study found only 3 people willing to donate. They suggested that a wider dissemination of the Muslim Law Council's fatwa should encourage a greater willingness to donate organs.

METHOD

AIMS AND OBJECTIVES

This study was a cross sectional study of the Muslim population in Birmingham. Questionnaires were prepared with the help of review of previous questionnaires used in similar studies. Input was also taken from the organ donation co-ordination team based in the Queen Elizabeth Hospital, Birmingham. The questionnaire covered the following topics:

1. What proportion of Muslims was aware of the existence of an organ donor register.
2. What proportion of Muslims was currently on the register.
3. What proportion of Muslims was planning to go on the register.
4. What proportion of Muslims were aware of any Islamic fatwa's regarding organ donation and what they think those fatwa's state.
5. Whether they would be willing to donate if they knew for sure that Islam allowed organ donation.
6. Whether they would accept on organ for themselves or for a family member in end organ failure.

The questionnaire was objective in that there were definite options for most of the questions from which the interviewees had to pick one or more than one.

Other information that was also taken from the participants included

- Age
- Sex
- Occupation
- Ethnicity

DATA COLLECTION

All the questionnaires were completed by interview. The study included Muslims at University, attending gyms and in the local community. The title and purpose of the study was firstly explained to the prospective subject. Following their acceptance to take part each question was addressed one by one, with the interviewer explaining any difficulties along

the way. If participants wanted other members of their family to fill in the questionnaire in private, this was allowed only if it was anticipated they had the ability to explain the questionnaire. This is one of the reasons that only 97 interviews were conducted; however a positive matter was that no individual refused to participate.

RESULTS

In total 93 Muslims of varying ethnic background chosen at random took part in the questionnaire/ survey, of which 63 were male and 30 female. This makes it the biggest study of its type.

Below is a summary of the results obtained:

- 93 subjects took part in the study
- None of the 93 participants were registered organ donors
- 69 (73%) of the subjects were aware of the organ donor register
- Lack of awareness of the organ donor register was most pronounced in the above 40-age group. (39%)
- Only 28% of the subjects claimed to be aware of an Islamic fatwa regarding organ donation.
- Proportionally twice as many males claimed to be aware of a fatwa than the women.
- 60% of the participants believed organ donation to be impermissible in Islam.
- Only 15% of the participants stated an interest in becoming registered organ donors, whereas 83% did not. 2% were unsure.
- Religious disapproval was given as the major reason for not donating (44%)
- Of those who were unwilling to donate, less than half (45%) said their opinion would change if they knew for sure Islam allowed organ donation, whereas 55% said their opinion would either not change or were unsure.
- 74% of participants expressed a willingness to accept an organ for themselves or a family member in the event of end organ failure.

DISCUSSION

In analyzing the above results it is worth noting that only 73% of the sample surveyed were aware of the existence of an organ donor register. This lack of awareness of the register was more pronounced in the over-40 age group, where only 39% were aware of it. This may be put down to the fact that it was this age group who arrived as the first generation of immigrants and have therefore the highest illiteracy rate. Obviously it is the awareness, or the lack of, which is the first hurdle in combating low donor rates. Naturally the awareness of a donor register will increase amongst this age group in the next ten years as a direct result of demographic transitions. However, it is important to point out the significance of enhancing the awareness of an organ donor register among this age as it is this age who are more likely to die within the next ten years or so and therefore donate. The awareness amongst the younger age group was satisfactory at 77%.

The survey also found that only a minority of both sexes in all age groups was aware of any definite fatwa/ rulings regarding organ donation. Only 36% of men and 17% of women said they had heard of or came across a specific ruling. However, when they were asked what they thought Islam said about organ donation, the majority of the sample, 60%, assumed it was impermissible. The results to this question show that even if people do not know the exact ruling on this subject there appears to be a tendency to jump to the conclusion of impermissibility. This points out either a lack of knowledge amongst Muslims about this specific ruling or a lack of discussion amongst the religious leaders, the imams, and community in general. Whatever the reason, this is yet another vital point which could play a pivotal role in enhancing the number of potential organ donors.

The questionnaire also asked the interviewees whether they were intending to become a donor in the future to which the majority, 83%, replied in the negative. The key reason given for the lack of enthusiasm for organ donation was the assumption that Islam forbids it, 44%. Other noteworthy reasons given were fear of post mortem, 16% and family disapproval, 6%. Of the entire group, 38% said they had never considered it. Hence, the next natural question to ask was “would their opinion change if they knew for sure that Islam allowed organ donation.” The response to this question was very interesting as less than half said that they would donate if they knew for sure that Islam allowed organ donation. This raises the question of the usefulness of all the

fatwas, which were previously mentioned. One may argue that at least by propagating the fatwas, 1 in 2 people might change their mind. But that is assuming that the aforementioned fatwas have a relevance to the majority of Muslims. 72% of the Muslims interviewed had not ever heard of these fatwas, which probably points to the fact that these Islamic bodies do not have a great impact on the majority of Muslims, otherwise they would have surely heard of them. Hence, this in part explains why the issuing of the fatwas has not had the desired impact of increasing donor rates amongst Muslims.

Lastly, the survey asked the public whether they would accept an organ for themselves or any member of their immediate family in end organ failure. 74% of the sample said they would accept an organ in end organ failure for themselves or for their family in end organ failure. This result gives rise to many ethical issues such as should anyone who is not willing to become a registered organ donor have the right to receive an organ in end organ failure? Whatever the answer, it is obvious from these results that there are some who would be happy to accept another persons organ but were not willing to donate their own. An approach to this dilemma may lie in amending the current legal status regarding this issue. Should the law ban patients from receiving organs in end organ failure if that patient is not already a registered donor? Should there be a 'deal' done between doctors and patients whereby the patient will be put on the waiting list for a transplant provided he/she will donate any healthy organs after death, whenever that may be.

CONCLUSION

It can be seen that the issue of the lack of willingness of Muslims to donate their organs remains an unresolved issue within the community of Birmingham, despite the work of the Birmingham Organ Co-ordination Team in conjunction with the UK Muslim Council. The attempts of these two bodies to increase the number of Muslim Donors has fallen flat, and it seems that this is because they have not been able to significantly challenge the beliefs of the Muslim

community of Birmingham. Part of this is because the bodies that have issued fatwas appear to be bodies not known or followed by the Muslim communities of Birmingham, as suggested by the fact that only 28% of the interviewees claimed to be aware of any fatwas on the permissibility of organ transplantation. It also can be seen that the Muslim community appear reluctant to donate their organs, for many reasons, even if they were sure that organ transplantation was permissible; more than half of the interviewees were in this category.

Therefore, the issue remains that not only are organ transplantations low amongst the Muslim population of Birmingham, there remains a lack of consistency in the views of this population. There is still a high proportion of Muslims, this study suggests 74%, that would be willing to accept an organ if it meant they could save their life. This means that unless something can be done to seriously affect the views of the Muslim population on the issue of organ transplantation, the medical challenges of helping those Muslims wanting organ transplantation remains. As already suggested earlier, perhaps a more harsher regime has to be enforced, whereby the Muslim community is advised that organ transplantation can only be offered as an option to them if they are willing to become a donor. Although this policy would be highly controversial, it would certainly eliminate the issue of Asians being disproportionately over-represented on the waiting lists for organ donors.

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