

THE INFLUENCE OF RELIGION ON ORGAN DONATION AND TRANSPLANTATION AMONG THE BLACK CARIBBEAN AND BLACK AFRICAN POPULATION - A PILOT STUDY IN THE UNITED KINGDOM

Cynthia Davis, BSc; Gurch Randhawa, PhD, BSc

Currently the demand for transplant organs, particularly kidneys, far outstrips the supply in the United Kingdom. This problem is particularly severe for the Black African and Black Caribbean populations who have a higher predisposition to end-stage renal failure. Several commentators have suggested that religious and cultural traditions may be the major determinant preventing Black Africans and Black Caribbeans from donating organs. An exploratory qualitative study using focus groups was undertaken with the aim of examining the influence of religion, among other things, on the extent and direction of public attitudes toward organ donation in a cross-section of the Black African and Black Caribbean populations in Lambeth, Southwark, and Lewisham.

In almost every focus group, religion and faith were expressed as issues that could prevent Black people from becoming organ donors. Organ donation was debated with caution on the basis of how their religious experience had influenced them. This finding suggests that the church and faith leaders could play a greater role in raising awareness of organ donation in these communities. Religious leaders can reach large numbers of people in a short space of time and will assist members of any group to understand more fully the religious stance on the subject matter. This education, in the long term, may lead to more people becoming organ donors. (*Ethn Dis.* 2006;16:281-285)

Key Words: Black African, Black Caribbean, Organ Donation, Religion, Transplantation

From the South Thames Transplant Coordination Service, King's College Hospital NHS Trust, Denmark Hill (CD); Institute for Health Research, Faculty of Health and Social Sciences, University of Luton, Luton (GR).

Address correspondence and reprint requests to Gurch Randhawa, PhD; Director; Institute for Health Research; University of Luton; Park Square; Luton; LU1 3JU United Kingdom; 01582 743797; 01582 743771; gurch.randhawa@luton.ac.uk

INTRODUCTION

At the end of 2002, >5500 patients were waiting for a transplant in the United Kingdom.¹ However, the continuing imbalance between supply of and demand for organs means that most of these patients will continue to wait. For the foreseeable future, this trend is unlikely to decrease unless the number of donors is dramatically increased. This issue is even more pertinent to the United Kingdom's Black African and Black Caribbean communities who experience greater inequalities in health and poorer access to services. Black African and Black Caribbean communities have a higher prevalence of type 2 diabetes: recent studies indicate a prevalence rate four times greater than that seen in Whites.² A further complication is that diabetic nephropathy is the major cause of end-stage renal failure (ESRF) in Black African and Black Caribbean patients who receive renal replacement therapy (RRT), either by dialysis or transplantation. Nationally, this higher relative risk, when corrected for age and sex, has been calculated in England as 3.7 for those with a Black African and/or Black Caribbean background.² Thus, not only are Black Africans and Black Caribbeans more prone to diabetes than Whites, they are more likely to develop ESRF as a consequence. This disparity creates a greater need for renal replacement treatment either by kidney dialysis or transplantation among Black Africans and Black Caribbeans. The situation is compounded further because their chances of receiving a transplant are reduced because of difficulties in tissue matching in cross-racial transplants and a shortage of donor organs. A number of studies show matching organs from White patients with Black

These studies suggested that religious beliefs deter them [Black African and Black Caribbeans] from donating their organs.⁷

African and Black Caribbean patients waiting for transplantation is more difficult.³⁻⁵ This finding is mainly due to problems with matching tissue type and blood group matching.³⁻⁵

In the short term, the number of Black Caribbean and Black African donors must increase, which can only be achieved by increased donor card carrying and signing on the donor register.⁶ In the absence of accurate information, speculation about the factors determining the low rate of organ procurement among the United Kingdom's Black African and Black Caribbean population has relied heavily upon findings from empiric studies conducted among Black Americans. These studies suggested that religious beliefs deter them from donating their organs.⁷

An exploratory study was therefore undertaken to examine the issues pertinent to organ donation, one of which was the influence of religion, in a cross-section of the Black African and Black Caribbean population of Lambeth, Southwark, and Lewisham (a large conurbation of London).

SUBJECTS AND METHODS

The fieldwork involved the use of focus-group discussions. We felt that

Table 1. Focus group composition

	Group	Racial Mix of Group	Religion	Age Range	Sex	Borough Represented	No. of Participants
1	African	Africans	Christians Muslim	18–60	Male Female	Lewisham Lambeth	10
2	Youth	Caribbeans African	Christians Non-faith	18–30	Male Female	Lewisham	10
3	Community	Black other African	All Christians	18–60	Male Female	Lewisham	4
4	Church Leaders	Caribbeans	Christians	31–60+	Male Female	Southwark/ Lambeth	6
5	Health Professionals	Africans Caribbeans	Christians	18–60+	Male Female	Lambeth, South- wark/Lewisham	11
6	Community	Africans Caribbeans	Christians Muslims Non-faith	18–60	Male Female	Lambeth, South- wark/Lewisham	21
7	Senior Citizens	Caribbeans	Christian	60+	Male Female	Lambeth	14
8	Community	African Caribbeans Mixed	Non-faith Christians	18–60+	Male Female	Lambeth, South- wark/Lewisham	20
9	Church Group	Caribbeans	Christians	31–60+	Male Female	Lambeth, South- wark/Lewisham	11
10	Muslim	Africans Caribbean	Muslims Christian	18–44	Male Female	Lambeth/South- wark	6
11	Senior Citizens	Caribbean African Mixed	Christians	44–60+	Male Female	Lambeth, South- wark/Lewisham	10

other methods, such as questionnaires or individual interviews, were unlikely to give us the depth of information required, without an increased amount of time and expense.

Eleven focus groups were established between January and March of 2002 to gather information about the attitudes toward organ donation among Black people living in the boroughs of Lambeth, Southwark, and Lewisham. An external evaluation consultant facilitated the meetings, assisted by the project manager (CD).

The meetings were conducted by using a topic guide, which was used to generate group discussion. Areas covered ranged from knowledge and awareness of transplantation to views of and attitudes toward organ donation.

Group Composition (Choosing the Sample)

A purposive sampling approach was used, and groups were chosen to reflect

the range of Black communities residing in the boroughs of LSL. The groups' compositions are highlighted in Table 1.

Specific groups such as church leaders, youth, health professionals, Muslims, Africans, and senior citizens were designated to ensure a wide representation of religious persuasions and cultures.

Recruitment of Groups

In order to have as wide a cross-representation as possible from within LSL, the study was advertised with posters in the community and personal invitations to community residents. Because of the nature of the subject and the apparent lack of interest, we targeted established community groups. Letters were sent to >200 community groups and churches, and follow-up visits were made to those who did not respond to the letter. As a result of this approach, 120 respondents were involved in the focus groups, with 4 to 21 people in each group.

The Group Discussions

Permission to tape record the discussion was sought from and given by the participants following an explanation by the facilitator before each session. The meetings lasted from 1 to 2 hours, and refreshments were provided. A complimentary gift voucher was given to volunteers as appreciation for their time and participation.

In order not to influence group participants' attitudes, the facilitator required the project manager to refrain from answering questions raised by group members during the discussions.

Data Analysis

The analysis of the discussion transcripts was undertaken in a similar manner to O'Brien's technique.⁸ This method involved the project manager's reading the transcripts and devising codes to represent the different topics and issues that were discussed. The transcripts were then annotated with

these codes so similar comments and observations could be identified and contrasting views and opinions could be juxtaposed. The grouping of the codes under certain headings offered not only a framework for analyzing the interview data in this way, it also provided an appropriate structure for the written discussion of the findings.

Limitations of Data Analysis

As referred to earlier, because recruiting people for the focus groups through general advertising was difficult, we used groups that were established. These groups included both of the senior citizens groups and the church members group. The interview transcripts were analyzed only by the project manager because of resource constraints.

RESULTS

Role of Religion

Most participants attending the focus groups had some kind of religious affiliation. Often during the focus groups, many of those who stated they did not presently belong to any religious group indicated that they had either been brought up in a religious setting or knew someone who belonged to a faith group.

All focus group discussions highlighted that religion was a factor influencing the decision to become an organ donor or not. Religion was often viewed as a barrier to organ donation, with some feeling unsure if their religion allowed them to become organ donors or whether it was "right with God."

"Some people, because of their religion, won't accept an organ." Female Caribbean, 18–30 yrs, FG8

"I'm allowed to accept, but I'm not sure if my faith allows me to give." Male African, 18–30 yrs, FG10

"The Koran says that we cannot donate when we die, only when alive. I think I

have read this." Male African, 18–30 yrs, FG10

On the other hand, the church leaders' group was very positive about organ donation and recognized some of the issues raised. One church leader of a Pentecostal group stated:

"A lot of Christians believe in the resurrection and they may feel that giving up part of their body will cause a problem in the resurrection. The bible says, 'If your hand or foot offends you, cut it off, for it is better to go into heaven with one hand or foot, than to go to hell with both.' This proves to me, that you will be accepted without your organs." Male Caribbean, 60+ yrs, FG4

"I believe that people refuse to participate because of their own fears, and they use religion to justify it when biblically, nothing is taught on this." Female Caribbean, 31–44 yrs, FG4

However, the strongest obstacle to organ donation in terms of religion was not what people perceived their faith had to say about it but how the individual interpreted his or her relationship with his faith's supreme being, particularly in times of sickness. Comments strengthening this belief came from approximately half of the groups.

"My aunt's close friend needed a heart and lung transplant. She saw herself as 'God's instrument' and believed that if it were his will, she would be healed. She saw her body as a whole unit, being given to her specifically, and did not believe in giving or taking organs from anyone else. She eventually died. Her friends were behind her decision not to have the organs." Male Caribbean, 18–30 yrs, FG3

"I have a very positive Christian experience, and believe that if my life was coming to an end, I would rather just let it go." Female Caribbean, 31–44 yrs, FG5

Within the church group, as one would have expected, the issue of faith and religion was very strong. Feelings about death being "God's will" were expressed frequently.

"I believe in healing and praying. If my organs fail, it may be God's way of saying it's time to go." Male Caribbean, 31–44 yrs, FG9

In most groups, people expressed a wish to remain whole as they expected to be resurrected, or come back in another life.

"I don't want half of my body buried and half to go to heaven." Male African, 45–60 yrs, FG1

"I believe in the afterlife. When I go I want to be buried intact so that I can come back whole." Male Caribbean, 45–60 yrs, FG2

Role of Culture

Regarding cultural issues, many of the focus groups (8 out of 11) expressed the view that Black people in general didn't like to talk about death and were very private about particular matters.

"We don't like to think about death, it's too final." Female Caribbean, 31–44 yrs, FG10

Among the African group participants, a few people mentioned traditional beliefs, which were seen as objections to donation.

"There are Africans of royal lineage that wouldn't mix blood no matter." Male African, 31–44 yrs, FG8

"In Africa if you're sick, you die. We do not think about 'I'll take something from you to live, or you can take something from me.' It's taboo. I think it will change very slowly." Male African, 45–60 yrs, FG8

One African participant felt that things must change.

"In Malawi the vice president needed a kidney, everyone was asked to consider

donation. So many cultural barriers came up like if you donate your organs you will die and the spirits will haunt you." *Male African, 31-44 yrs, FG1*

This respondent continued by saying:

"Because of the public response, I became very curious about organ donation and why people were so reluctant to donate something to help another." *Male African, 31-44 yrs, FG1*

Role of Discrimination

Most groups (six out of 11) did not overtly mention prejudice/discrimination as an issue for not becoming organ donors. However, in the other focus groups comments were raised that indicated that this was potentially an obstacle to why people did not wish to become donors.

"The attitude of Whites is off-putting. They don't know anything about Black people." *Male African, 18-30 yrs, FG1*

"You want to give your organ? It will never reach the Black people. . . . They will give it to their own." (*Same male as above*)

A perception of how Black people have been mistreated by the medical profession was brought up in one group.

"I do not trust White doctors. Many Blacks have died because of them." *Female Caribbean, 44-60 yrs, FG*

"I've experienced the way Blacks are treated in hospitals and I don't trust White doctors." *Female Caribbean, 60+, FG7*

Influence of Family and Friends

Some respondents mentioned the influence of families' attitudes to organ donation. Participants felt that because people did not have enough information about donation, they could be more persuaded by their friends or

family members who may tell them they were "mad" or may "die more quickly" if they became organ donors. One participant stated even though she may, herself, be reluctant to donate, her family may be able to influence her otherwise. Others mentioned the fear of family objection and rejection if they chose to become an organ donor, particularly in African families.

DISCUSSION

This short exploratory study provides a glimpse of the experiences of Black people in LSL with regard to organ donation and the influence of religion. By sampling purposively and making the different Black Caribbean and Black African communities the focus of the research, this study looks to advance our limited knowledge of these communities' views toward organ donation. This study should be seen as exploratory but is nonetheless an initial step toward establishing greater knowledge and understanding of the issues affecting the low donation rate in the Black African and Black Caribbean population in the United Kingdom.

In almost every focus group, religion and faith were expressed as issues that could prevent Black people from becoming organ donors. This finding was noticeably true in the youth group, where many of the young people, while not affiliated to any religious group, still held very closely the principles with which they had been brought up or which were prevalent in their homes or lives. As a result, they treated organ donation with caution on the basis of how their religious experience had influenced them. This finding suggests that the church and faith leaders could play a greater role in raising awareness of organ donation in these communities. In the United States, this approach has been used successfully, where churches play a prominent role in

In almost every focus group, religion and faith were expressed as issues that could prevent Black people from becoming organ donors.

promoting organ donation among Black Americans.⁹

Although current literature states that all main religions see organ donation as a good and noble act, this fact is not always known or appreciated by members of the laity. Many of these reports often quote from only one person's perspective, namely the priest, rabbi, or minister.¹⁰ Many leaders themselves are often inadequately informed on the subject of organ donation, and the subject is not one that is often discussed in churches or places of worship.

However, not all Black people attend church, and innovative ways have been suggested to reach all groups, such as, for example, targeting places such as discos, clubs, pubs, colleges and universities, sports centers, and local Black businesses and organizations. Advertising on radio shows with a large Black audience also provides useful ways of reaching Black people. Black people who have had transplants need to come together and be advocates for organ donation by sharing their experiences. This multi-pronged, community-based approach has been successfully adopted among African Americans in the United States and among the Aborigines in Australia.^{9,11}

In organizing dissemination campaigns, care needs to be taken in specifying the target population, selecting the persons who will communicate the campaign appeal, designating the method of delivery, and deciding on the content of the appeal.¹² This study indicates that appeals for Black organ donors may be more effectively com-

municated by employing a grass-roots, community networking approach.

Prejudice, Fear, and Mistrust

Mistrust of the medical profession by Black people is not a new phenomenon and plays a large part in refusal to donate organs. This finding has raised questions in some minds as to how, in the light of a campaign for Black people, can one be sure that organs retrieved from Black people will go to Black people? In order to instil confidence in those who may decide to become organ donors, the correct message must be given. This message should be one that informs about the importance of the similarity in tissue types that affects organ donation, and it this parameter affects to whom organs will go, not the color of the donor or recipient. This type of information may be crucial to the understanding and willingness of Blacks in agreeing to organ donation and emphasizes the need for a thorough education program.

CONCLUSION

In view of the UK government's drive to raise the profile of organ donation in the Black community and increase the number of those on the organ donor register, we believe this pioneering study is both timely and important. It has sought to identify some of the prevailing obstacles to organ donation. The findings of this report are in keeping with many re-

search studies that have been conducted in the United States on attitudes toward organ donation in Black Americans.^{7,9}

Church leaders have a role to play in the dissemination of information regarding organ donation. Gallagher asserts that "one sermon or counselling session with a religious leader who is educated about donation would be a powerful statement for future potential donors and donor family members."¹³ Religious leaders can reach large numbers of people in a short space of time and will assist members of any group to understand more fully the religious stance on the subject matter.

ACKNOWLEDGMENTS

This study was made possible with a grant from the Special Trustees of Lambeth, Southwark, and Lewisham Health Authority as part of the work of the African Caribbean Organ Donation Awareness Project (ACODAP).

REFERENCES

1. UK Transplant. *UK Transplant Activity Report 2001*. Bristol: UK Transplant; 2001.
2. Raleigh VS. Diabetes and hypertension in Britain's ethnic minorities: implications for the future of renal services. *BMJ*. 1997;314:209-212.
3. Gjertson DW, Terasaki PI, Takemoto S, Mickey MR. National allocation of cadaveric kidneys by HLA matching: projected effect on outcome and costs. *N Engl J Med*. 1991; 324(15):1032-1036.
4. Terasaki PI. The HLA-matching effect in different cohorts of kidney transplant recipients. *Clin Transpl*. 2000:497-514.
5. Rebellato LM, Arnold AN, Bozik KM, Haisch CE. HLA matching and the United Network for Organ Sharing Allocation System: impact

of HLA matching on African-American recipients of cadaveric kidney transplants. *Transplantation*. 2002;74(11):1634-1636.

6. Randhawa G. Developing culturally competent renal services in the United Kingdom: tackling inequalities in health. *Transplant Proc*. 2003;35:21-23.
7. Callender CO, Bey AS, Miles PV, Yeager CL. A National Minority Organ/Tissue Transplant Education Program: the first step in the Evolution of a National Minority Strategy and Minority Transplant Equity in the USA. *Transplant Proc*. 1995;27:1441-1443.
8. O'Brien K. Improving survey questionnaires through focus groups. In: Morgan DL, ed. *Successful Focus Groups: Advancing the State of the Art*. London: Sage; 1993.
9. Callender CO, Hall MB, Miles PV. Increasing living donations: expanding the National MOTTEP community grassroots model. *Minority Organ Tissue Transplant Education Program*. *Transplant Proc*. 2002;34(7):2563-2564.
10. Gallagher C. Religious attitudes regarding organ donation. *J Transplant Co-ordination*. 1996;6:186-190.
11. Hoy WE, Wang Z, Baker PR, Kelly AM. Reduction in natural death and renal failure from a systematic screening and treatment program in an Australian Aboriginal community. *Kidney Int Suppl*. 2003;83:S66-S73.
12. Khan Z, Randhawa G. Informing the UK's South Asian communities on organ donation and transplantation. *Eur Dialysis Transplant Nurses J*. 1999;25:12-14.
13. Gallagher C. Religious outreach for organ and tissue donation. *J Transplant Co-ordination*. 1998;8:60-62.

AUTHOR CONTRIBUTIONS

Design and concept of study: Davis
Acquisition of data: Davis
Data analysis and interpretation: Davis, Randhawa
Manuscript draft: Davis, Randhawa
Supervision: Randhawa