

CPD feature

Diversity in Organ Donation and Transplantation

Mark R D Johnson

Emeritus Professor, MSRC, De Montfort University Leicester, UK

Since April 2014, a total of 3,028 people in the UK have received a transplanted organ which has enabled them to live normal lives. Unfortunately the demand for transplants far outstrips the availability of donated organs and to date there are 6,872 people on the waiting list (NHS Blood and Transplant (NHS-BT) <http://www.organdonation.nhs.uk/>). Members of Black and South Asian groups, the two largest minorities in the country, will often have to wait up to a year longer than their white counterparts because of a persistent shortage of suitable donated organs; some may die while waiting for an organ to become available.

Black and South Asian people are more likely to need an organ transplant than the rest of the population, as they are more susceptible to illnesses such as hypertension, diabetes and certain forms of hepatitis, all of which may result in irreversible damage to kidneys or other organs. However, care has to be taken to ensure that a donated organ matches the recipient's blood group and tissue type. Transplants are more likely to be successful if there is a close match between the two. Ethnic background is therefore also important. Certain blood types, for example, are more commonly found in people of African, or Asian heritage while others are commoner in those of European ancestry. Matching is very important because transplants are not without risks. An individual's body may reject an organ and cause serious, acute illness; infection, bleeding, poor function of the transplanted organ and the side effects of immunosuppressive drugs are all possible in the post-operative period.

A key factor in this situation appears to be a reluctance to donate. Data from NHS-BT (UK Transplant) sources indicate that 66% of Black, South Asian and some other minority communities living in the UK refuse to give permission for their relatives' organs to be donated compared to 43% of the rest of the population. Religion and religious beliefs are contributing factors in sustaining this inequality. Black Africans and Muslim communities are most likely to believe, inaccurately, that their faith does not permit organ donation, or sometimes blood transfusion, but in fact but all the major religions of the UK support the principles of organ donation and transplantation. According to African Caribbean Leukaemia Trust (ACLT) (www.aclt.org), 8% of the 4,644 black respondents surveyed felt that their family would disapprove of donating stem cells, compared to only 1% of the majority population; 12% felt it could be dangerous to donate.

Religious perspectives on organ donation

In recent years, NHS-BT has produced a range of educational materials such as leaflets, posters, videos and podcasts in different languages to increase awareness of transplant related issues. Some of these are accessible through the links included in this feature and the main points are summarised below with a link to the relevant NHS-BT publication.

Buddhism

There are no injunctions in Buddhism for or against organ donation. The death process of an individual is viewed as a very important time that should be treated with the greatest care and respect. The needs and wishes of the dying person must not be compromised by the wish to save a life. Each decision will depend on individual circumstances. Central to Buddhism is a wish to relieve suffering and there may be circumstances where organ donation may be seen as an act of generosity. Where it is truly the wish of the dying person, it would be seen in that light.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/buddhism_and_organ_donation.asp

Christianity

Organ donation can be considered by Christians as a genuine act of love, which has been endorsed in recent times by leaders of all the major denominations.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/christianity_and_organ_donation.asp

This leaflet is available in both English and Polish.

Hindu Dharma

There are many references that support the concept of organ donation in Hindu scriptures. Daan is the original word in Sanskrit for donation meaning selfless giving. In the list of the ten Niyamas (virtuous acts) Daan comes third.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/hindu_dharma_and_organ_donation.asp

This leaflet is available in English, Gujarati, Hindi, Punjabi and Tamil.

Islam

In Islam there are two schools of thought with regards to organ donation. The human body, whether living or dead, enjoys a special honour and is inviolable. Islamic law emphasises the preservation of human life. The general rule that 'necessities permit the prohibited' (al-darurat tubih al-mahzurat), has been used to support human organ donation with regards to saving or significantly enhancing the life of another providing that the benefit outweighs the personal cost that has to be borne. The UK based Muslim Law (Shariah) Council resolved in an authoritative Fatwa issued in 1995 that:

- The medical profession is the proper authority to define signs of death.
- The Council accepts brain stem death as constituting the end of life for the purpose of organ transplantation.

- The Council supports organ transplantation as a means of alleviating pain or saving life on the basis of the rules of the Shariah.
- Muslims may carry donor cards and in the absence of a donor card or an expressed wish to donate their organs, the next of kin of a dead person may give permission to obtain organs from the body to save other people's lives.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/islam_and_organ_donation.asp

This leaflet is available in English, Bengali, Gujarati, Punjabi, Urdu, Arabic and Somali

Judaism

In principle, Judaism sanctions and encourages organ donation in order to save lives. This principle can override Jewish objections to any unnecessary interference with the body after death, and the requirement for immediate burial, although some more Orthodox followers, notably in the Hasidic community, insist that the body should be buried whole, and will collect any spilled blood for interment as well.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/judaism_and_organ_donation.asp

Sikhism

The Sikh philosophy and teachings place great emphasis on the importance of giving and putting others before oneself. Seva or selfless service is at the core of being a Sikh; to give without seeking reward or recognition. Seva can include donation of an organ to another person. There are no taboos attached to organ donation in Sikhism nor is there a requirement that a body should have all its organs intact at or after death.

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/leaflets/sikhism_and_organ_donation.asp

Other resources

How we are raising awareness in Black and South Asian communities www.organdonation.nhs.uk/campaigns/other_campaigns/black_and_asian/index.asp

Organ donation and the Asian community

www.organdonation.nhs.uk/campaigns/other_campaigns/detail.asp?id=3

Organ donation and the black community

www.organdonation.nhs.uk/campaigns/other_campaigns/detail.asp?id=2

Does the colour of my skin make a difference?

http://www.organdonation.nhs.uk/how_to_become_a_donor/religious_perspectives/

Reflective activities

End of life

AJ is a young Nigerian man who was seriously injured in a

road traffic accident on his way home from the local mosque. He has been in the intensive care unit for several days but is not expected to recover from his injuries.

How would you raise the issue of organ donation with his family?

Other minorities

Whilst there is an increasing amount of information and resources about ethnicity, genetics, and faith/culture very little attention is paid to other aspects of diversity such as age, disability, gender or sexual orientation. The following vignette addresses one of these aspects.

SL is a 40-year-old woman who has 4th stage renal failure following treatment for kidney disease. She is considered appropriate for transplantation and has come to clinic to discuss this. She is accompanied by another younger woman who has agreed to be a living non-related donor. The notes state only that this woman is a 'friend' and there is no information about her relationship to the patient.

How would you approach this situation?

The women are, in fact, in a civil partnership. What factors might the couple need to consider before proceeding?

Resources

Professor Gurch Randhawa, University of Bedfordshire presents an action plan to tackle the issues referred to in this feature, including work with Faith leaders, education for communities and professional health workers, and general public-awareness raising, was based on work by

http://www.organdonation.nhs.uk/newsroom/news_releases/printTemplate.asp?releaseId=351. This has informed the national plan for the future of the services: <http://www.nhsbt.nhs.uk/to2020/>

There are many resources for professionals in a website curated by the UK Clinical Lead for Organ Donation <http://www.clodlog.com/>

The African Caribbean Leukaemia Trust (www.aclt.org) was set up in response to one family's attempt to find a stem-cell donor for a much-loved son. It has campaigned and raised awareness, and brought many BME donors onto the donor registers, and works with other agencies to continue this work. One short educational video - #CouldYouBeMyMatch is available on Youtube: <https://www.youtube.com/watch?v=VVz654rZ-pg>

Other resources are available through the National BAME Transplant alliance: www.nbta-uk.org.uk/

Prof Maggie Sque, University of Wolverhampton, provides a real-life interview with the father of an organ donor <https://vimeo.com/23919896>. While not specifically approaching issues of diversity, it raises questions and indicates the depth of emotion and the significance of donation to relatives.

The African Caribbean Leukemia Trust (ACLT – www.aclt.org) is probably the UK's premier action group in relation to registering minority ethnic donors for bone-marrow and other forms of tissue donation. A number of other resources are associated with their work:

There is a near-absence of materials on infertility and gamete donation among minority ethnic groups in Europe. One research project which attempted to address this issue (Culley et al. 2007) also prepared some resources to support would-be parents from the South Asian community, and these are available as .pdf leaflets and audio files in the four main South Asian languages <http://www.dmu.ac.uk/research/research-faculties-and-institutes/health-and-life-sciences/reproduction-research-group/the-asfert-study.aspx>

See also:

<http://www.dmu.ac.uk/documents/research-documents/health-and-life-sciences/reproduction-research/endopart/tryingforababypunjabileaflet.pdf>

and

<http://www.dmu.ac.uk/documents/research-documents/health-and-life-sciences/reproduction-research/endopart/asfertshortreport.pdf>

Previously in Diversity and Equality in Health and Care

Brown, E. (2014) Supportive Care for people with kidney disease: ethnic and cultural challenges. *Journal of Renal Care, Supplement, Vol 40, pp1-46*

Clark, M D, Gumber, A, Leech, D, Moro, D, Szczepura, A K, West, N, Higgins, R M (2009). Prioritizing patients for renal transplantation?: Analysis of patient preferences for kidney allocation according to ethnicity and gender. *Diversity in Health and Care, 6 (3), 181-191.*

Culley L, Hudson N, Johnson MRD, Rapport F, Katbamna S (2007) I know about one treatment where they keep the egg somewhere: British South Asian community understandings of infertility and its treatment. *Diversity in Health & Social Care 4, 2:113-121*

Gooldin, S (2011) Cultural competence and ethical incompetence: notes from a study of the new reproductive technologies in Israel. *Diversity in Health & Care 8,1: 45-54*

Hudson N (2012) Researching infertility in British South Asian communities: reflecting on intersections of ethnicity, age, gender and reproductive identity *Diversity and Equality in Health and Care 9,3 :191-199*

O'Neill, Kristal R; Hamer, Helen P; Dixon, Robyn (2013) Perspectives from lesbian women: their experiences with healthcare professionals when transitioning to planned parenthood *Diversity & Equality in Health & Care 10,4 pp. 213-222*

Randhawa G, Brocklehurst A, Pateman R, Kinsella, S, Parry V (2010) Utilising faith communities in the UK to promote the organ donation debate: the views of UK faith leaders *Diversity in Health & Care 7,1:57-64*

Further Reading List

Alkhwari, FS, Stimson GV, Warrens AN. (2005) Attitudes towards transplantation in UK Muslim Indo-Asians in West London. *American Journal of Transplantation, 5: 1326-1331.*

All Party Parliamentary Kidney Group. (2012) Improving kidney donation and transplantation within UK Black and Minority Ethnic communities. London, available at

http://www.kidney.org.uk/documentlibrary/Home_Dialysis_Report.pdf

Culley, L. Hudson, N. Rapport, F. Johnson, M. Bharadwaj, A. 2006 Public Perceptions of Gamete Donation in British South Asian communities (End of Grant report: ESRC grant RES-160-25-0044, 2005-2006)

Davis C & Randhawa G. (2006) The influence of religion of organ donation among the Black Caribbean and Black African population – a pilot study in the UK. *Ethnicity & Disease, 16: 281-5.*

Department of Health. (2008) Organs for Transplants: A report from the Organ Donation Taskforce. London, Department of Health.

Department of Health. (2008) The potential impact of an opt-out system for organ donation in the UK – An independent report from the Organ Donation Taskforce, London, Department of Health.

EUMIDON - ESF International Workshop on Minority Migrants and Human Tissue Donation / Transplantation; Birmingham, September 2004 <http://www.esf.org/generic/1925/03017Report.pdf>

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.*

Hudson N, Culley L, Rapport F, Johnson MRD, Bharadwaj A 2008 “Public” perceptions of gamete donation: a research review’ *Public Understanding of Science OnlineFirst, October 1, 2008* at: <http://pus.sagepub.com/cgi/rapidpdf/0963662507078396v1> (Print version Vol 18,1 :61-77 2009)

Hudson N, Johnson MRD 2004 Human Tissue and Blood or Organ Donation, Transplantation and Minority Ethnic Communities : A Literature Review, Working Paper No. 6 (For the European Science Foundation International Exploratory Workshop, 'EUMIDON: Europe's Migrants and Human Tissue Donation.) Leicester: Mary Seacole Research Centre http://www.dmu.ac.uk/Images/seawor6%20Organ%20and%20Tissue%20Donation_tcm6-11033.doc

Johnson MRD 2009 ‘End of life care in ethnic minorities; providers need to overcome their fear of dealing with people from different backgrounds’ *BMJ 338 :489-490 doi:10.1136/bmj.a2989*

Morgan M, Hooper R, Mayblin M, Jones R. (2006) Attitudes to kidney donation and registering as a donor among ethnic groups in the UK. *Journal of Public Health, 28: 226-234.*

Morgan, M. et al. (2012) Attitudes to deceased organ donation and registration as a donor among minority ethnic groups in North America and the UK: a synthesis of quantitative and qualitative research. *Ethnicity & Health, 1-24.*

National Institute for Health and Clinical Excellence

(2011) Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. London: National Institute for Health and Clinical Excellence.

Oliver, M. et al. (2011) Organ donation, transplantation and religion. *Nephrology Dialysis Transplantation*, 26: 437-444.

Randhawa G. (1998) The impending kidney transplant crisis for the Asian population in the UK. *Public Health*, 112: 265-68.

Randhawa, G. (2011) Achieving equality in organ donation and transplantation in the UK: Challenges and solutions. London: Race Equality Foundation.

Randhawa, G. et al. (2010). Faith leaders united in their support for organ donation: findings from the UK organ donation taskforce study. *Transplant International* 23(2): 140-146.

Randhawa G (2013) Faith Engagement and Organ Donation Action Plan, Institute for Health Research, University of Bedfordshire, with NHS Blood and Transplant

Sims, J. M. et al. (2012) Overcoming barriers to registering as an organ donor among minority ethnic groups. London, Race Equality Foundation.

West Midlands Specialised Commissioning Team: Organs for Transplants: an analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation, October 2010.