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Who waits longest for a kidney? Inequalities in access to kidney transplantation

Black and Asian Minority Ethnic (BAME) groups are over-represented on active kidney transplantation waiting lists and have relatively long waiting times. This inequality arises from a particularly high need for kidney transplantation combined with a low rate of deceased donation among BAME groups, which limits the availability of a well matched graft. This article outlines the major barriers to donation and describes initiatives to increase donation and transplantation.

Kidney transplantation currently accounts for 82% of all solid organ transplants undertaken in the NHS, with 62% involving a kidney from a deceased donor. However, the need for kidney transplantation far exceeds the availability of donor organs, particularly for the Black/Black British population (mainly of African and Caribbean origin) and the Asian/Asian British population (mainly of Indian, Pakistani and Bangladeshi origin). Taken together, BAME groups comprise 30% of transplant waiting list patients, but only around 11% of the population (Table 1).

Waiting times are also relatively long for BAME patients, with a median waiting time for kidney transplant of over 1,400 days; approximately one year longer than that for the White population.¹ This has implications for quality of life and survival, as well as increasing costs to the NHS, given that the majority will receive dialysis as an alternative form of renal replacement therapy.²

Factors impacting the waiting list problem

The high unmet need for kidney transplantation among BAME groups partly reflects a high incidence of end-stage renal failure (ESRF), with the relative risks of ESRF among Black and South Asian populations estimated to be three to four times that of the White population.³ Moreover, although rates of living donation are similar to the White population, rates of deceased donation

are relatively low among people of Black and South Asian origin, who comprise just under 4% of deceased donors.

The low donation rate is associated with a low rate of registration on the organ donor register (ODR), with only 3.5% from the BAME population. In addition, only 33% of BAME families approached consented to donation, compared with 61% of White families.¹ This is of particular significance for members of ethnic minorities whose blood group and human leucocyte antigen (HLA) tissue type are less common in the White population, as matching is undertaken to reduce the requirements for immunosuppressive medication and risk of graft failure. However, the greater emphasis recently given in allocation to waiting time has led to more equitable access by the BAME population.

Another approach to the waiting list problem is to reduce rates of chronic kidney disease (CKD) and its progression to ESRF. This requires public health interventions to reduce rates of type 2 diabetes, obesity and hypertension, which have a relatively high prevalence among Black and South Asian populations, together with effective screening and medical management to avoid progression to renal failure. There is some evidence that preventive strategies that specifically target BAME groups may be beginning to yield benefits in reducing risks of CKD.^{4,5}

Reducing the gap between need and availability of well-matched organs also requires increasing donation rates among the BAME community, as highlighted by the organ donation taskforce (ODT), which stressed the urgent requirement to identify and implement effective methods to promote organ donation to Black and minority ethnic populations.⁶

Barriers to organ donor registration

Research has identified five main barriers to registration as an organ donor among minority ethnic groups.^{7,8} These are summarised below.

Rates of deceased donation are relatively low among people of Black and South Asian origin

Table 1. Active kidney transplant waiting lists by known ethnicity¹

Ethnicity	Percentage of active kidney transplant waiting list, 2013*	Percentage of UK population (2011 census)
White	69.8	87.2
Asian/Asian British [†] : Indian, Pakistani, Bangladeshi	17.1	4.9 [‡]
Black/Black British	9.8	3.0
Asian/Asian British: Chinese	1.4	0.7
Other ethnic group	1.7	2.3

*Excludes transplant patients with ethnicity not reported; [†]group referred to here as South Asian [‡]Includes mixed multiple ethnicity as a separate category

Knowledge of organ donation and registration

Lack of knowledge of organ donation and the process of registration is identified as the major factor limiting registration. Such limited knowledge has continued in the UK despite five major national campaigns since 1999 and a range of community-based activities focusing on informing BAME groups about organ donation.⁹ This situation appears to be associated with a lack of perceived relevance of the campaigns and their visual representations, which may go unnoticed rather than being actively rejected.

Faith and cultural beliefs

All faith groups in the UK formally support organ donation in principle;¹⁰ although people from minority ethnic groups are significantly more likely to be uncertain whether organ donation is acceptable to their faith. This reflects both their limited knowledge and familiarity with the topic, as well as differing interpretations of scriptures. For example, certain verses in the Quran lead to a positive interpretation of donation as a form of doing good for others, whereas some passages relate to doing harm to one's body, which is prohibited under Islam. People from different faith groups also often have particular worries, such as how organ donation affects the afterlife and the timing of burial. Such conflicting interpretations and mixed beliefs further impact on willingness to engage with organ donation.

Bodily concerns

Some reservations regarding organ donation are linked to concerns about the body, both during and after donation. This includes not wanting the body to be cut, so as to return to God 'whole', and a desire by some people to return to their home country at death with their body intact. Worries about bodily disfigurement causing distress among family members are also common, partic-

ularly when faith or cultural requirements involve the deceased being displayed in an open casket or an expectation that relatives will wash and dress the body.

Family influence

Reluctance to discuss organ donation with family members is common and reflects superstitions around discussing death, parents not wishing to think about the death of children, and younger people worrying about offending their elders.

Trust in doctors and the health system

People from Caribbean minority ethnic groups have been identified as having particular concerns about whether medical professionals can be trusted to do all they can to prolong life if the patient is known to be registered to the ODR. Other concerns relate to possible unethical practice involving the use or retention of organs, linked with media scandals, and worries about the fairness of the organ allocation system.

Barriers to family consent to donation

Family consent is known to be influenced by existing beliefs and attitudes to donation, together with satisfaction with end-of-life care and the organ donation process.^{11,12} Positive influences on family consent include a clear understanding of brain death, satisfaction with communication, support and the donation discussion, and whether family members believe that everything possible was done for their relative. Relatives are also more likely to consent when the deceased's wishes are known to support this, either because they have joined the ODR or discussed their attitudes and wishes with family members.¹³

Conclusions: the way forward

Providing equitable access to kidney transplantation is challenging and requires effective measures both to reduce rates of ESRF and increase

Box 1. Requirements of effective community interventions to increase deceased donation among minority ethnic groups

- General minority ethnic campaigns could be replaced, or complemented, by messages that focus more specifically on the concerns of specific ethnic, cultural or faith groups rather than broader categories, such as Asians or Muslim.
- Personal case studies relating to the experiences of families who have consented to donation, recipients of a deceased donor organ and those on the waiting list would enhance the perceived relevance and acceptability of deceased donation and are, therefore, likely to have greater impact.
- Trained members of the local community are generally easier for people to relate to and have an important role both in delivering educational messages and serving as 'champions' for donation.
- Educational approaches tend to be more effective where there are immediate opportunities to join the ODR.
- Initiatives to promote deceased donation could build on, and partner with, other campaigns, such as those for blood, tissue or bone marrow donation, and draw on the lessons of effective approaches in other countries.

rates of deceased donation. Strategies to increase donation rates occur at three levels, which are described below.

System changes

Increasing donation and transplantation rates are often argued to require a fundamental change from the current opt-in system of informed consent that exists in the NHS, to a system of presumed consent, in which individuals are considered to be potential donors unless they opt out. The ODT examined this issue in detail and concluded that there was insufficient evidence to justify a move to presumed consent, and that the major influence on donation rates is the organisation of donation services rather than a system of presumed consent.⁶

The health systems in England, Scotland and Northern Ireland have retained an opt-in system of informed consent and implemented a series of changes recommended by the ODT to increase the efficiency, acceptability and effectiveness of the donation service. The introduction of a presumed consent model in Wales is planned for September 2015 and will provide information on the acceptability and outcomes of this system in an NHS context.

Another innovative system change is the Israeli model, introduced in January 2010, which aims to motivate organ donation through preferential status in the allocation of organs for transplantation for those who have registered, or have first degree relatives who have registered, as organ donors.¹⁴ The effects are currently being followed with interest, although there are concerns that it shares many of the ethical and practical disadvantages of an opt-out system and moves away from the fundamental NHS principles of allocation based on medical need.

Organisational changes

One of many changes introduced following the ODT's report has been the appointment of specialist nurses for organ donation (SN-OD). A key aspect of this role is to provide long-term contact with families, beginning when a relative is identified as a potential donor, and collaboration with clinicians in the consent discussion and post-donation follow up. Families place considerable value on such support,¹² and consent rates are shown to be higher when the consent discussion involves an SN-OD than when undertaken by the clinician alone.¹ However, it is important that other members of the intensive care team also have the training and resources to be able to provide appropriate cross-cultural communication and support. Such training has not traditionally been available in the UK. However, a new video-

Key points

- Black and Asian ethnic minorities are over-represented on the active waiting list for kidney transplantation.
- A reduction in waiting times requires the relatively high rate of end-stage renal failure among minority ethnic groups and the low rate of deceased donation to be addressed.
- Community education is more effective than mass media campaigns alone in increasing organ donor registration, and should be targeted at the beliefs and concerns of specific groups and their stage of readiness to change.
- Consent to donation is influenced by family satisfaction with end-of-life care and the quality of communication. Development of culturally sensitive training for healthcare professionals and enhanced service provision are recommended to address this.

based training package to promote cultural competence was developed as part of the Donation, Transplantation and Ethnicity (DonaTE) programme and is now freely available.¹

Community interventions

There is considerable experience in adapting mainstream health promotion interventions to minority ethnic groups, including the Programme Theory of Adapted Health Promotion Interventions, which aims to achieve health promotion interventions directed to minority ethnic groups that are feasible, acceptable and equitable.¹⁶ Research evaluating interventions to increase organ donor registration among minority ethnic groups has produced similar findings and indicates that educational interventions are more effective than mass media interventions alone. It also identifies key requirements of effective educational interventions to increase deceased donation among minority ethnic groups (see Box 1), which have informed two ongoing projects utilising Kidney Research UK's Peer Educator initiative ■

Declaration of interest

The authors declare there is no conflict of interest.

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References

1. NHS Blood and Transplant. *Organ donation and transplantation: activity report 2012/13*. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2012_13.pdf (last accessed 10/03/15)
2. NHS Blood and Transplant. *Cost-effectiveness of transplantation*. www.organ-donation.nhs.uk/newsroom/fact_sheets/cost_effectiveness_of_transplantation.asp (last accessed 10/03/15)
3. Roderick PJ, Raleigh VS, Hallam L, Mallick NP. The need and demand for renal replacement therapy in ethnic minorities in England. *J Epidemiol Community Health* 1996; **50**: 334–339.
4. Mukhopadhyay B, Frouhi NG, Fisher MB, Kesson CM, Sattar N. A comparison of glycaemic and metabolic control over time among South Asian and European patients with type 2 diabetes: results from follow-up in a routine diabetes clinic. *Diabet Med* 2006; **23**: 96–98.
5. Wilkinson E, Randhawa G, Farrington K *et al*. A multi-centre qualitative study exploring the experiences of UK South Asian and White diabetic renal patients. *BMC Nephrology* 2012; **13**: 157.
6. Department of Health (DH). *Organs for transplant: a report from the organ donation taskforce*. London: DH, 2008.
7. Morgan M, Kenten C, Deedat S. 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. *Ethn Health* 2013; **18**: 367–390.
8. Morgan M, Deedat S, Kenten C. Explaining low rates of organ donation among minority ethnic groups: A holistic perspective. In: Weimar W, Boss MA, Busschbach JVV (eds). *Organ transplantation: Ethical, legal and psychosocial aspects - expanding the European platform*, vol 2. Lengerich: PABST Science Publishers, 2011.
9. Sims JM, Kenten C, Deedat S, Randhawa G, Morgan M. *Overcoming barriers to registering as an organ donor among minority ethnic groups*. London: Race Equality Foundation, 2012.
10. NHS Blood and Transplant. *Religious perspectives on organ donation*. www.organ-donation.nhs.uk/how_to_become_a_donor/religious_perspectives (last accessed 10/03/15)
11. Simpkin AL, Robertson LC, Barber VS. Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *BMJ* 2009; **338**: b991.
12. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001; **286**: 71–77.
13. NHS Blood and Transplant. *Taking organ transplantation to 2020: a detailed strategy*. www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf (last accessed 25/03/15)
14. Sharif A. Prioritising existing donors to receive organs would boost donation from ethnic minorities. *BMJ* 2013; **347**: f5036
15. Morgan M, Kenten C, Sims J, Newton T. Improving communication and consent for organ donation among minority ethnic groups: development and evaluation of a hospital based intervention. In: Weimar W, Boss MA, Busschbach JVV (eds). *Organ transplantation: Ethical, legal and psychosocial aspects - expanding the European platform*, vol 3. Lengerich: PABST Science Publishers, 2014.
16. Liu J, Davidson E, Bhopal RS *et al*. Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis. *Health Technol Assess* 2012; **16**: 1–469.

Major funding boost for chronic kidney disease graphical surveillance pilot

Outcomes in patients referred late for renal replacement treatment are particularly poor. Early referral of those with progressive chronic kidney disease (CKD) may reduce the rate of decline and so delay, or avoid, the need for dialysis or a kidney transplant. Early identification of patients with deteriorating kidney function should allow more timely access to specialist care and create significant opportunities to improve outcomes.

ASSIST-CKD (A programme to Spread estimated glomerular filtration rate graph Surveillance for the early Identification, Support and Treatment of people with progressive Chronic Kidney Disease) is a new, UK-wide collaborative quality improvement project supported by the Health Foundation and led by Kidney Research UK.

The project, which starts in spring 2015, involves eight to ten renal units and surrounding GP practices, and will use data from routine kidney function tests to generate graphs of estimated glomerular filtration rates (eGFR) over time. For those patients with deteriorating kidney function, an eGFR graph report is sent to their GP, with a prompt that specialist advice may be needed. Patients with more stable CKD can be discharged from the outpatient kidney clinic knowing that their kidney function will continue to be monitored via their eGFR graph.

ASSIST-CKD is based on a successful community-wide system at the Heart of England Foundation Trust (HEFT) in Birmingham. Since 2005, when eGFR graph surveillance was introduced, the number of patients starting dialysis per year at HEFT has fallen by 16%, compared with an increase of 8% in England as a whole. The HEFT renal unit also has the lowest presentation rate for dialysis in the UK (5.7% in 2012/13, compared with the UK average of 18.6%). Feedback has been positive, with 74% of GPs finding the eGFR graph reports useful, and 41% having changed their management of patients as a result.

Project lead, Dr Hugh Gallagher, said, 'This quality improvement intervention has enormous potential to provide better and safer care by identifying people with CKD who are most at risk, so they can be referred to secondary care at the right time, for the right treatment in the right care setting. We hope to demonstrate that the programme can be effective in other areas outside of the West Midlands, which would create a powerful case for universal adoption of the service across the UK.'

To find out more
about the ASSIST-CKD
project, please contact
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