South Asian patients awaiting organ transplantation in the UK

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Abstract

Background. The fate of ethnic minority patients with end-stage renal failure is often a concern due to differences in disease profile, blood groups and difficulties in organ matching. This is an issue for Asian patients in particular, and there are more Asians on the UK transplant waiting list than expected.

Methods. We reviewed the available evidence along with recent data from UK Transplant in an attempt to summarize the current situation and to suggest improvements.

Results. While Asians comprised 13.6% of the UK waiting list, only 0.9% of non-heart-beating donors and 1.8% of heart-beating donors were Asian. Refusal rates from relatives for deceased donation were 78.7% for Asians and 31.8% for Caucasians, but approach rates were 89.4% and 95.1%, respectively. However, 7.3% of living donors were Asian.

Conclusions. Changes to the UK National Kidney Allocation Scheme in 2006 may improve access to organs for Asian patients. The interaction of biological, cultural and organizational factors affecting Asian patients needs to be considered carefully to ensure that these patients are not disadvantaged.

Keywords: ethnicity; organ transplantation; renal transplantation

Introduction

The organ donor shortage in the Asian (Unless otherwise stated, ‘Asian’ refers to those persons of Indian/Bangladeshi/Pakistani or other Asian ethnic origin. It includes those persons who identify themselves as being ‘Asian’ and ‘Asian British’. UK Transplant data categorize ‘Chinese/Oriental’ as a separate ethnic group, and these persons are not included within the ‘Asian’ group.) community remains particularly acute and consequently disadvantages Asian patients awaiting organ transplantation. The organ allocation scheme may have exacerbated this in the past and, as a result, was changed in 2006. Additionally, concerns have been expressed about the effect of institutional racism and failings within the organ procurement process [1]. This study considers the current situation for Asians in the UK who require a renal transplant and how the current excess of Asians awaiting transplantation might be addressed.

The donor crisis

Although 3513 patients received an organ transplant in 2008–09, which represents an 8.6% rise compared with 2007–08, the current number of patients on the active transplant list is 7877 [2]. Unavailability of organs for transplantation is an international phenomenon, but the situation in Asia is particularly serious, with deceased-donor donation rates <5 per million population [3]. Full ethnicity data collected by UK Transplant since 2002 reveal that the majority of deceased solid-organ donors are white (95.2%), with Asians comprising 1.9% [2]. A disparity exists between the large number of Asian patients on organ transplant waiting lists and the small number of Asian donors (Figure 1). In 2009, 15% of 7190 active kidney transplant waiting list patients were Asian—a percentage higher than expected given that Asians comprise 4% of the UK population [4].

Repercussions of the Asian donor shortage

The shortage of Asian organ donors directly disadvantages Asians in terms of histocompatibility and ABO blood group matching [5,6]. Focusing on kidney transplantation, for which the Asian population has the highest demand, under the previous organ allocation scheme HLA matching was of prime importance. This meant that Asians were potentially disadvantaged because they share fewer HLA antigens with the donor population than Caucasians. The new Kidney Allocation Scheme (2006) should theoretically prioritize ‘difficult to match’ patients. It is based on five tiers, through which highly sensitized and HLA-DR homozygous adult patients, and paediatric patients, receive greater priority. Within adult patient tiers, patients are further prioritized with points allocated according to factors...
including waiting time, donor–recipient HLA and blood group matching. Asians benefit through rarer HLA antigens being defaulted to commoner types. The new scheme is designed to reduce the importance of HLA matching in allocation, although its effect in addressing inequalities can only be assessed after several years. Additionally, blood grouping dictates that Asian patients on the transplant waiting list have less chance of receiving a kidney. Blood group B patients (25% of Asians versus 9% of Caucasians) can only receive organs from group O and B donors. However, the kidney allocation system subtracts points for blood group B patients when the donor group is O to avoid disadvantaging group O patients, who can only receive a group O kidney.

Factors influencing donation rates

It may be argued that the most suitable organs for Asian patients need to come from Asian donors. Deceased-donor donation among Asians is uncommon. Asians comprised 5 of the 571 non-heart-beating donations between April 2006 and June 2009 [2]. Relatives of 31.8% of white and 78.7% of Asian/Asian British heart-beating donors, and 37.5% of white and 79.1% of Asian/Asian British potential non-heart-beating donors refused consent between April 2006 and June 2009 (Figures 3 and 4). Despite the number of live kidney donors increasing from 374 (2001–02) to 929 (2008–09), the UK Asian community continues to comprise ~7% of the total live kidney donors (Figure 2). This figure may seem low, but given that Asians comprise 4% of the total UK population [4], the live kidney donation rate among Asians is high (although, clearly, the demand for organs is higher in the Asian population).

Factors attributed to reluctance to donate by some members of ethnic minorities include the following:

(i) religious myths/misperceptions [7],
(ii) lack of community transplant awareness/the need for transplantation [7],
(iii) distrust of medical community [7],
(iv) racism [7],
(v) traditional beliefs/customs which are unsympathetic to organ donation [8],
(vi) worries that organs may be used for other purposes such as medical research [9],
(vii) concerns about leaving the body ‘intact’ after death [9].

Fig. 1. Ethnicity of heart-beating kidney donors and recipients, 1 April 2008–31 March 2009, and transplant list patients at 31 March 2009 in the UK (created using the data from [2]).

Fig. 2. Ethnicity of live kidney donors in the UK from transplants 1 April 2001–31 October 2009, by financial year (created using data from the Statistics and Audit Department at UK Transplant).
(viii) lack of confidence that medical teams would try as hard to save a donor’s life [9], and
(ix) generalized lack of trust in health systems/professionals [9].

In a study of attitudes to organ donation among South Asians in Southall (Middlesex), 16% of participants carried an organ donor card compared with 28% reported for the general population, but 48% of non-card carriers said they

**Donation after cardiac death**

Fig. 4. Breakdown of the UK donor data by ethnicity for donation after cardiac death, comparing potential donor data before and after revision of the UK organ allocation scheme (created using the data from the Statistics and Audit Department at UK Transplant).
Asian patients awaiting organ transplantation

would offer one of their kidneys if a close relative had kidney failure [6]. Smith states that there is a continuing disjunction between the high numbers of general public who report being ‘hypothetically’ favourable towards the concept of organ donation and the low numbers that actually donate, indicating that this ambivalence is particularly severe among some ethnic minorities. It may be argued that Asians remain emotionally removed from the issues related to organ donation, despite agreeing with them in principle [10].

Towards alleviating the donor crisis

The need for suitable organs among Asian patients requires donation from the Asian community. Initiatives using Asian live donor coordinators have been shown to increase living donation rates among Asians [11]. Randhawa states that emphasis should be on a ‘reconsideration of the presently inadequate approaches to organ procurement and on devising and supplementing these with more appropriate ones’ [12]. Encouragingly, a recent report by the Organ Donation Taskforce emphasized the Asian donor shortage and identified barriers to organ donation. Recommendations to increase organ availability for transplantation included the following:

(i) establishment of a UK-wide Organ Donation Organisation with individual Trust clinical donation champions and donation committees,
(ii) establishment of an independent UK-wide network of dedicated organ retrieval teams,
(iii) implementation of local policies constructed around national guidelines,
(iv) introduction of minimum notification criteria for potential organ donors,
(v) monitoring of donation activity in all Trusts with rates of potential donor identification, referral, family approach and consent to donation,
(vi) financial reimbursement to Trusts facilitating donation, and
(vii) mandatory training for staff involved in the treatment of potential organ donors [13].

The UK Potential Donor Audit, established by UK Transplant in 2003, was part of several measures designed to improve organ donation rates [14] and highlighted a significant difference in the white and non-white refusal rates for potential heart-beating donors. The Transplant Activity in the UK Report 2006–07 identified the high proportion of relatives refusing consent as the biggest obstacle in improving the supply of organs for transplantation [2]. However, emphasis on the relatives’ refusal rate detracts from other concerns within the procurement process. On further analysis of UK Transplant data, it is apparent that some potential donors are lost earlier in the procurement process. Next of kin were approached or made an approach in 94% of 3583 potential heart-beating donors and 87% of 1786 potential donations after cardiac death, where solid-organ donation was considered, but inter-ethnic group differences exist in this approach rate (Figures 3 and 4). The reason behind this difference is unclear, but reasons may include language barriers and staff perception that agreement to donate is unlikely.

There is a clear dearth of published studies pertaining to UK healthcare professionals’ attitudes towards the organ procurement process in ethnic minorities. The majority of research has been in the USA and has focused on the African-American community. Guadagnoli et al. examined whether patients’ race was associated with their families being approached for organ donation and agreeing to donate. It was hypothesized that the behaviour of hospital staff may be related to the racial disparity in rates of organ donation [15]. African-American patients were less likely to be approached for donation than families of white patients, and among the families approached, those of African-American patients were less likely to agree to organ donation. Reasons why hospital staff approached families of African-American patients less often included differences in how hospital staff relate to families and perceive families’ disposition towards donation, and rates at which patients are identified as medically suitable for donation.

This indicates the crucial role that healthcare professionals play in the request process and how this is influenced by perceived and enacted preconceptions based on ethnicity. As Siminoff and Arnold affirm, stereotypes held by healthcare professionals regarding whether a person will or will not donate lead to a reluctance to ask, a lower consent rate and reaffirmation of stereotypes [16]. More research is needed to investigate why this disparity in inter-ethnic group approach rate exists in the UK.

Siminoff et al. provided empirical support for the hypothesis that ‘blacks’ lack of trust in the procurement system contributes to lower rates of donation [17]. White families were more likely to be correctly perceived as receptive to donation, while black families viewed as receptive were less likely to engage in discussions about donation. Blacks expressed more negative attitudes towards the healthcare system and perceived that they may not be treated fairly and/or that the organ allocation system was inequitable. Indeed, Siminoff et al. state that these perceptions are reflective of the institutionalized racism (‘the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people’ [18]) many blacks have faced when dealing with the healthcare system, and such findings may also be applicable to Asians in the UK.

The evolving Asian community

In the future, organ donation rates will be directly influenced by the attitudes and beliefs developing in the younger
Asian community [8]. Spign er et al. set out to solicit beliefs about trust in physicians and the medical system regarding organ donation and transplantation and to examine deterrents to donation. Distrust in the medical system, of physicians, of the organ allocation system or of religious reservations about organ donation was evident but acted as less prominent deterrents to donation among non-white high school students than have been reported with adults [19]. The rationale behind the different perceptions of non-white teens as compared with their adult counterparts was that they may ‘have been less exposed to a history of what several health scholars recognize as the impact of racial/ethnic discrimination on a group’s health beliefs and knowledge’.

Conclusions

In addressing the plight of Asians in the UK needing transplantation, several factors are important. Rates of donation for deceased-donor organs, especially after cardiac death, are low among Asians, while living donor rates are reasonable. Significant inter-ethnic group differences in consent refusal rates exist, reflecting the need for attitudinal change towards organ donation within the Asian community, but differences in approach rates by healthcare professionals are also important. Complete equity in organ allocation will always be difficult, but a positive step has been the move away from a strong emphasis on HLA matching which disadvantaged ethnic minorities in the past. However, the effectiveness of the new scheme in addressing inequalities is yet to be fully evaluated.

The UK is recognized as a diverse, multicultural society, and as such, its healthcare system must respond to this diversity. As Rawaf states, ‘the healthcare system must tackle the issues of racism and discrimination as these continue to contribute to both the health and health concepts of people from...ethnic minority groups’ [20].

Improving the organ donation rate among Asians in the UK requires a cohort of strategic interventions which need to be underpinned by recognition of the pivotal role played by distrust in the medical system, the impact of diversity and cultural awareness of healthcare providers, and the importance of improved cross-cultural communication.

Acknowledgements. We thank Claire Counter and Phil Pocock, Statistics and Audit (UK Transplant, NHS Blood and Transplant, Bristol) for providing the data; Chris Rudge (National Clinical Director for Transplant, Department of Health, London) for commenting on the final draft; and Dr R.G. Smith (Research Associate, Division of Medicine, Imperial College London) for sharing his knowledge and discussing his current research on organ donation among Asians. The authors acknowledge financial support from the Department of Health via the National Institute for Health Research (NIHR) comprehensive Biomedical Research Centre award to Guy’s and St Thomas’ NHS Foundation Trust in partnership with King’s College London and King’s College Hospital NHS Foundation Trust.

References


Conflict of interest statement. N.M. is a consultant in a large transplant centre with a high ethnic population, and is a guarantor.

Received for publication: 30.4.10; Accepted in revised form: 31.8.10