Transplanting an ethnic community: approaches to the crisis

Andrew R. Ready

The Renal Unit, Queen Elizabeth Hospital, Birmingham B15 2TH, UK

Introduction

Many parts of Europe have in recent years been subject to large-scale immigration which has dramatically altered the nature of the population. For example, during the 1960s and 1970s, the UK experienced large-scale immigration from the countries of the former British Empire and has now become home to a number of non-indigenous ethnic groups. To obtain employment, most immigrants settled in the industrial areas of the Midlands and North of England. Birmingham, in the West Midlands, is the second largest city in the country (Greater Birmingham population ~5.5 million) and has a prestigious industrial history. Accordingly, much of the UK’s immigration has been focused on Birmingham, with the result that ~22% of the region’s population is now non-Caucasian. The largest of Birmingham’s non-indigenous ethnic groups originates from the Indian sub-continent, and this Indo-Asian community now accounts for 14% of the region’s population (750,000 individuals).

Demography of renal transplantation in the Indo-Asian community

In common with most other immigrant populations worldwide, the British Indo-Asian community poses a number of healthcare problems. However, of particular importance is its high incidence of renal failure, seen in both the adult [1] and paediatric populations [2], which has been reported to be almost twice that observed amongst Caucasians [1,3]. Whilst the reasons for this remain enigmatic, its effect is to stimulate a high demand for renal replacement therapy. As a result, 25% of dialysis patients in the Birmingham renal failure programme are of Indo-Asian origin, a disproportionately high number when compared with their representation in the region’s population (14%). This, in turn, leads to an exceptional demand for renal transplantation which cannot be met. Consequently, only a small percentage of Indo-Asian patients ever receive a renal transplant.

Previously, little data has been available to either document or explain the extreme imbalance between the demand for kidneys by the Indo-Asian population and their supply. However, a number of studies performed in Birmingham may explain this predicament and suggest possible solutions. The first of these sought, through a retrospective analysis of our patient and organ donor databases, to identify the magnitude of the demand for transplantation by the Asian community and to estimate the level to which this was likely to rise by the year 2000. It was found that between 1995 and 1997, Indo-Asian patients accounted for 30% of the patients on the renal transplant waiting list (RTWL), more than double the representation of these individuals in the general population. However, during the same period, Indo-Asian patients accounted for only 13% of the total patients receiving renal transplants. The shortfall existing between the demand for transplantation and the actual supply of kidneys is therefore considerable.

ABO blood groups and HLA antigens in Indo-Asians

The low level of transplantation occurring in the Indo-Asian community appears to be related to distribution differences in ABO blood groups and HLA tissue types occurring between UK donors and the Indo-Asian community. The most significant of these differences concerns blood group B which occurs in 35% of Birmingham Indo-Asians. However, group B occurs in only 8% of UK donors, a frequency almost identical to that found in the UK Caucasian population from which virtually all UK donors arise. Blood group B Indo-Asian patients therefore regularly join the RTWL but are rarely transplanted, with the result that the number of blood group B patients awaiting a transplant continually grows. Accordingly, 45% of the Indo-Asian patients on the Birmingham RTWL are currently group B, i.e. almost half of the Indo-Asian RTWL patients presently waiting are seeking group B kidneys that become available in only eight of every 100 donations.

Correspondence and reprint requests to: Mr Andrew R. Ready, Consultant Surgeon, The Renal Unit, Queen Elizabeth Hospital, Birmingham B15 2TH, UK.
A very close correlation also exists between the HLA antigens occurring most frequently in UK donors and those required by Caucasian RTWL patients. Again, this is not surprising since most UK donors are Caucasian. This correlation is less defined when available donor antigens are compared with those required by Indo-Asian RTWL patients. In this situation, a number of important antigens occurring frequently in Indo-Asian patients are only rarely observed in UK donors, i.e., the UK donor pool has a shortage of antigens, at the three HLA loci, that are observed frequently in Indo-Asians. Such HLA matching problems exacerbate the plight of Indo-Asian patients since even if suitably ABO-matched kidneys do become available, the chance of a good HLA match is limited. As a result, Indo-Asian patients are unlikely to be chosen to receive a kidney which is usually better matched to a Caucasian recipient.

Impact on Indo-Asians on the renal transplant waiting list

These factors suggest that the UK donor pool fails to provide kidneys most biologically suitable for Indo-Asian patients and, moreover, that the most appropriate kidneys for Asian patients would come from Indo-Asian rather than Caucasian donors. However, cadaveric organ donation occurring within the Indo-Asian community is virtually unknown. Between 1990 and mid-1997, the Birmingham unit procured a total of 670 kidneys of which only four (0.6%) arose from Indo-Asian donors. This has been blamed, at least in part, on the persistence of traditional beliefs and customs, in the community, which are unsympathetic to organ donation. The age distribution of the Asian population and the low number of Indo-Asians admitted to intensive therapy units [4] might also be contributory factors.

Regardless of aetiology, the lack of suitable cadaveric kidneys to supply the demands of Indo-Asian patients has significantly affected the dynamics of the RTWL. Hence, whilst the number of Asian patients transplanted has remained static during the period 1990–1996 at ~10 patients per annum, the number of Indo-Asian patients joining the RTWL per annum has continued to grow. Consequently, the annual growth rate of RTWL as a whole has been 6.4% but for Indo-Asian patients is four times greater at 24%. This makes Indo-Asian patients the most rapidly growing subgroup on the list. This growth rate shows no sign of decline and, if sustained, 50% of patients on the RTWL will be of Indo-Asian origin by the year 2000. Almost half of these patients can be expected to be blood group B and, unless major changes occur in the composition of the UK donor pool, they have little chance of receiving a transplant. Potential Indo-Asian transplant recipients, therefore, face long periods on dialysis with the knowledge that they have little chance of receiving a suitable kidney. They also recognize the increased risks of exhausting their vascular access and understand that they may be removed from the RTWL without ever receiving a kidney due to failing health or advancing age. Moreover, they regularly see fellow dialysis patients receiving a kidney before them. Since most of these recipients are Caucasians who have often been on the RTWL for a shorter time, it is not surprising that a feeling of discrimination may develop. These factors all serve to reduce further the quality of life for Indo-Asian dialysis patients and may lead to desperate measures such as purchasing kidneys abroad.

A number of patients on the Birmingham RTWL have taken this action sometimes with catastrophic results [5].

Economic implications

The failure to provide kidneys for the growing Asian dialysis population also has major economic implications. It is estimated that an excess cost of $3.6 million is incurred for every 50 patients maintained on dialysis for 5 years rather than transplanted. By the year 2000, ~250 Indo-Asian patients will be on the Birmingham RTWL and if they continue to be transplanted at the rate of 10 per annum, as has occurred for the past decade, then only 50 of the patients will receive transplants during the subsequent 5 years. Two hundred patients will, therefore, remain on dialysis during this period, incurring an excess cost of $14.7 million. Renal transplantation in the Indo-Asian community is by any measure destined to become a human and economic crisis. This is particularly regrettable since it has been our experience that Indo-Asian patients who do receive a kidney have outcomes which compare favourably with their to non-Asian counterparts and that despite often serious language difficulties, they have shown excellent compliance with treatment. A solution is therefore required which allows the benefits of transplantation, currently enjoyed by a few Indo-Asian patients, to be extended to the majority who currently languish on the RTWL.

Approaches to resolve the impasse

One possible solution is to redefine the process of allograft allocation. For example, it has been suggested that HLA matching requirements should be reduced for any patient, irrespective of ethnic origin, who has been waiting for >2 years [6]. Whilst this proposal may reduce the waiting time for some patients, it is unlikely to help the many Indo-Asian patients for whom blood group rather than HLA matching is the principal barrier. A further solution may involve distributing group O kidneys to long waiting time group B patients. In most instances, this would simply divert kidneys away from better matched recipients with the result that the long-term potential of these kidneys may not be maximized. Changes in allocation practice may, therefore, ease the plight of some long wait patients, including some
We have recently assessed these attitudes in a questionnaire survey of young Birmingham Asians. The resulting survey group of 202 English-speaking, first generation Anglo-Asian individuals representing Islam, Sikhism and Hinduism, in proportion to their representation in the community.

The responses given by these young people initially appeared encouraging, with 92% appearing to understand the concept of organ transplantation fully, whilst 53% indicated a willingness to donate after their death. However, donor card carriage by these individuals was only 5%, and more than half (55%) considered transplantation an unacceptable practice. Furthermore, 70% felt that their views would, in the event of their death, be overruled by their elders, who would veto organ donation even if a strong view to the contrary had been expressed by an individual during their life. Although a wide range of personal reasons were given by those individuals not willing to donate, the single most frequent reason was that donation went against their religion. This finding appears to represent confusion occurring between the guidance given by ecclesiastical leaders and the interpretation made by ordinary followers, since all three of the religions included in the survey have philosophies sympathetic to cadaveric donation. This confusion appears to be most prominent amongst the Muslim community, since 57% believed that their religion did not allow cadaveric donation whilst 53% believed their religion was even against the receiving of cadaveric organs.

This is particularly disappointing in Birmingham where transplant co-ordinators negotiated the issue of a Fatwa with the Islamic Law Council of Britain which strongly supported cadaveric donation. By contrast, Sikhs and Hindus appeared clearer and less divided on these issues, 70% and 95% acknowledging that their religions allowed cadaveric donation and the receiving of cadaveric organs respectively. The importance of religious guidance was emphasized further by the finding that <30% of young Asians felt it would be acceptable to donate if their religion were perceived to be against the practice. However, >60% would consent to donate if their religion were considered as pro-transplantation.

The overall impression gained from the survey was that young members of the Asian community are more sympathetic to organ donation than their elders but that religious principles will remain an important influence on their attitudes to donation. However, most religious objections, especially amongst Muslims, appear to arise from confusion rather than genuine dogma. In the past, public education programmes presenting the general benefits of transplantation to ethnic groups have proved unsuccessful in increasing donation from the Indo-Asian community. The findings of this survey suggest that the limited resources available for such education would be better utilized on programmes targeted at the younger people, with the objective of clarifying their religion’s teaching on donation and transplantation.

### Live related donation

Nevertheless, past evidence suggests that increasing Indo-Asian cadaveric donation will be a slow process, probably too slow to remedy the crisis presently confronting many renal units. Live related donation, by contrast, has the potential to provide an immediate increase in available Indo-Asian kidneys. Whilst this has become an increasingly utilized alternative in Birmingham, the demand for this service has come mainly from the families of Caucasian patients. Indo-Asian families have not yet presented in significant numbers despite the fact that Indo-Asian families tend to be large, supportive and have extended networks from which suitable donors would be expected to arise. However, many Asian families still remain unaware of the special problems faced by their relatives, and to kindle their interest in live donation it is necessary to reach out to them with the appropriate information. This must be given with sensitivity since it is vital that Indo-Asian families, who may already feel marginalized, do not consider themselves the object of further discrimination through excessive pressures to find a donor from within their number. Furthermore, the rights of all family members must be safeguarded, particularly those, including women, who might be placed under undue pressure to become donors. Guidance on living related transplantation should therefore be given to Indo-Asian patients and their families in a manner sympathetic to their cultural background, ideally by a transplant coordinator recruited from their own community. This individual should counsel every Indo-Asian patient on the RTWL in unambiguous terms about the specific problems they
Approaches to transplanting an ethnic community

face in obtaining a transplant and the possible option of living related transplantation. This should be done in the patient’s preferred language, in an appropriate cultural setting and, where possible, in the presence of other family members. This approach has now been adopted in Birmingham to the appreciation of both Indo-Asian patients and their families who, possibly for the first time, feel well informed about their problems and empowered to help in developing a solution. As a result, there is growing interest in live related, and indeed spouse, donation. A number of live related procedures have now been performed where previously there were none, and more families are coming forwards for investigation. Furthermore, the publicity generated by these initial Indo-Asian live related procedures has been used as a means of educating the Asian community on transplantation issues.

Despite these encouraging developments, it must be recognized that live related transplantation alone is unlikely to solve all of the problems faced by Indo-Asian patients awaiting a renal transplant, but it is the part of the solution that can be instigated immediately. Changes in allocation of organs will also help a number of patients but, in the long-term, the burden of Indo-Asian patients will only be reduced when sufficient organs are donated by the Indo-Asian community itself. Public education programmes must, therefore, be targeted accurately to remove confusion over religious issues, inform the Asian community of the crisis it faces in renal transplantation and identify its responsibility to provide donated organs either through cadaveric or live related donation. These messages initially may be difficult for the community to confront, but can be balanced by the information that the majority of donated Indo-Asian kidneys would be used for Indo-Asian recipients. Softer approaches have proved unsuccessful in the past, and to repeat such campaigns would simply waste limited resources and be a disservice to the Indo-Asian community itself.

Acknowledgements. The author wishes to thank Jacki Trafford, Antony Hooker, Dr David Briggs, Psyche Bailey and Rachel Blackshaw for their invaluable assistance in the Birmingham Indo-Asian transplant programme.

References