Prioritizing patients for renal transplantation?: Analysis of patient preferences for kidney allocation according to ethnicity and gender

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Research paper

Prioritising patients for renal transplantation? Analysis of patient preferences for kidney allocation according to ethnicity and gender

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What is known on this subject
- There is a lack of information on the preferences of renal patients generally for different priority criteria for renal transplantation.
- Ethnic minorities, including South Asians, black Africans and Caribbeans, are more susceptible to renal disease, and there are lower levels of organ donation in these communities.
- Ethnic-minority groups are therefore disadvantaged if allocation is primarily directed towards recipients who can be closely tissue matched with donor organs.

What this paper adds
- The analysis provides information about patient preferences and patients' willingness to decide between different priority criteria for transplantation using discrete choice experiments.
- The analysis demonstrates that South Asian and non-white ethnic-minority patients have preferences that differ from those of other patients, and they would not prioritise patients with closer tissue matches or younger respondents. This is in contrast to other patients who are not in these ethnic-minority groups.
- Although there is evidence that preferences for prioritising transplants may differ between male and female patients, gender-related differences in preferences are not particularly pronounced.

ABSTRACT

Revisions to UK transplant allocation policy in 2006 marked a policy shift towards ascribing higher priority to people who had been waiting for a long time for transplants, and to young adults, at the expense of emphasising tissue match between donor and recipient. This benefited members of ethnic minorities because of a shortage of donors from some ethnic groups. However, the change was informed by dated research which was not specific to the UK, and which failed to address ethnic or gender-related differences in preferences.

Preference information was elicited using discrete choice experiment (DCE) questionnaires (in English, Punjabi, Hindi, Bengali, Gujarati and Urdu) from 908 patients (508 males and 397 females). Of the 908 repondents, 96 were members of ethnic-minority groups, namely white ethnic minorities (27/908) and non-white ethnic minorities (69/908), including 50 South Asians. Priority criteria included length of time spent waiting for a transplant, quality of the donor–recipient tissue match, number of

adult and/or child dependants of the recipient, and whether the recipient had diseases that affected their life expectancy or quality of life.

Econometric results provided evidence that preferences differed slightly according to gender, but differed to a greater extent according to ethnic origin. In significant contrast to other patients, members of non-white and South Asian ethnic minorities did not tend to prioritise recipients with a good tissue match, nor, unlike patients more generally, did they tend to prioritise younger recipients. Non-white and South Asian ethnic minorities were also less likely to prioritise those with moderate rather than severe diseases affecting life expectancy. These results reinforce the case for recognising differences in ethnic-minority group preferences in transplant allocation policy.

Keywords: choice experiment, ethnicity, gender, renal transplant

Introduction

In March 2008, a total of 6784 patients in the UK awaited renal transplants, but in 2007–2008 only 1249 patients received cadaveric (deceased donor) transplants, and 831 patients received live donor transplants. The growing imbalance between demand for and supply of transplants led to the 2008 Transplant Workforce Report (Department of Health, 2008), which outlined initiatives to facilitate a 50% increase in cadaveric transplants within five years. Despite this, demand will exceed supply, especially among members of ethnic-minority groups who are more susceptible to diseases linked to renal disease necessitating transplants (Raleigh, 1997; Churak, 2005; Davis and Randhawa, 2006; UK Transplant, 2006). They are also less likely to obtain closely matched transplants (Higgins *et al*, 1997; UK Transplant, 2006). The increased risk among members of ethnic-minority populations, compared with white patients, of developing end-stage renal disease (Churak, 2005) is partly related to the higher prevalence of type 2 diabetes. A UK study indicates a prevalence among black African and Caribbean patients that is 3.5 times higher than that among white patients (Raleigh, 1997). South Asians are also more susceptible to diabetes and heart failure leading to renal disease (Bennett and Savani, 2004). Greater demand for renal transplants in these communities is matched by reduced rates of organ donation (Bennett and Savani, 2004).

Therefore, systems that prioritise on the basis of donor and recipient tissue matching will disadvantage some ethnic groups.

Improved anti-rejection drugs have reduced the importance of tissue matching in determining transplant success, so other criteria now merit greater consideration (Koene, 2002). Moreover, by applying discrete choice experiments (DCEs), it is possible to quantify trade-offs between different priority criteria. A DCE study of this kind has already been undertaken in relation to liver transplantation (Ratcliffe and Buxton, 1999; Ratcliffe, 2000a). In this paper we report differences in preferences between non-white ethnic-minority patients and other patients, and between South Asian patients and other patients. We also consider whether these preferences vary according to gender.

Materials and methods

DCEs involve respondents making a series of choices about which one of two hypothetical transplant recipients who differ in their characteristics should receive a kidney. Using DCEs, the weight that respondents give to differences in characteristics can be quantified. The steps involved in undertaking a DCE are summarised below.

Pilot exercise

We interviewed 60 respondents (including eight members of ethnic-minority groups), consisting of 41 patients, 16 healthcare professionals, one donor, one carer and one renal consultant's secretary. These respondents completed a DCE questionnaire and ranked potential priority criteria for renal transplantation. All 60 respondents in the pilot exercise came from the University Hospitals of Coventry and Warwickshire (UHCW) NHS trust.

Attributes and levels: the final DCE

Attributes relate to the different hypothetical characteristics of transplant recipients, but these were based on a qualitative exercise informed by discussions between the lead researcher, other researchers, the grant-holder and UHCW medical staff. However, findings from the pilot exercise, including the significance or non-significance of attributes following data analysis, respondents' rankings of attributes in ranking exercises, and their general feedback, informed the selection of attributes and levels for the final questionnaire. Final attributes and levels included the following:

- **Length of time spent waiting for a transplant:** levels included were one month, two years or ten years. The coefficient on the variable *waiting time* indicates utility for each 1-year reduction in recipient waiting time.
- **Quality of tissue match:** levels included:
  – a non-favourable match with an average of 86% 12-month kidney survival post-transplant
  – a favourable match with an average of 89% 12-month kidney survival post-transplant
  – a perfect match with an average of 90% 12-month kidney survival post-transplant.
  The coefficient on the variable *tissue* indicates utility for each 1% improvement in kidney survival.
- **The number of child or adult dependants of the recipient:** levels included zero, one or four dependants. The coefficient on the variable *dependant* indicated utility from prioritising to people with dependants, for each additional dependant.
- **Recipient age:** levels included 20, 45 or 65 years. The coefficient on the attribute *age* indicated utility for each one-year reduction in recipient age.
- **Recipient diseases that affect life expectancy:**
  – the variable *disease1* indicated utility from transplanting to a recipient having no diseases, other than kidney disease, affecting recipient life expectancy rather than a moderate disease such as uncontrolled hypertension or obesity plus kidney disease
  – the variable *disease2* indicated utility from transplanting to a recipient having a moderate disease affecting life expectancy, such as uncontrolled hypertension or obesity, rather than a severe disease affecting life expectancy, such as heart attack, diabetes with complications, or stroke.
  The difference between a person with no disease affecting their life expectancy and one with severe disease is the sum of significant coefficients on *disease1* and *disease2*.
- **Recipient diseases that affect quality of life:**
  – the variable *ill1* indicated utility from transplanting to a recipient having no diseases other than kidney disease affecting quality of life, rather than a moderate disease such as mild asthma with kidney disease
  – the variable *ill2* indicated utility from transplanting to a recipient having a moderate disease affecting quality of life, such as mild asthma with kidney disease, rather than a severe disease affecting quality of life, such as kidney disease plus severe arthritis.
  The difference between a person with no disease affecting their quality of life and one with severe disease is the sum of significant coefficients on *ill1* and *ill2*.

Final questionnaire

The DCE design was sourced from leaders in the field (Street *et al*, 2005). It is a 'main effects' design, and preferences are inferred from 18 choices for specific attributes. The design did not involve the use of a constant comparator. Half of the choices went into questionnaire version A, the remainder went into version B, and we distributed equal numbers of each. It was orthogonal, and checks (Spearman's and Pearson's correlation coefficients) confirmed this. The questionnaire was available in English, Pubjabi, Hindi, Bengali, Gujarati and Urdu. The questionnaires elicited information on gender and posed a question about ethnicity (see Figure 1).

Questionnaire distribution

A total of 20 000 flyers with Freepost reply envelopes were enclosed in the UK National Kidney Federation's publication *Kidney Life*, inviting people to request questionnaires, including alternative-language versions if required. As we did not receive a large enough sample of ethnic-minority patients from the postal questionnaire, a bilingual researcher (Dr Anil Gumber) obtained 18 additional responses from members of ethnic-minority groups at Ealing NHS Trust and five additional responses from members of ethnic-minority groups at University Hospitals of Coventry and Warwickshire NHS Trust.

Which of the following ethnic groups do you consider that you belong to? *(Please tick one box only):*

White (British)   ☐

White (Irish)   ☐

White (any other white background)   ☐
(please describe) ....

Mixed (white/black Caribbean)   ☐

Mixed (white/black African)   ☐

Mixed (white/South Asian)   ☐

Any other mixed background   ☐
(please describe) ....

Black or black British (Caribbean)   ☐

Black or black British (African)   ☐

Black or black British (any other background)   ☐

South Asian or South Asian British (Indian)   ☐

South Asian or South Asian British (Pakistani)   ☐

South Asian or South Asian British (Bangladeshi)   ☐

South Asian or South Asian British (any other   ☐
background)

Chinese   ☐

Any other ethnic group   ☐
(please describe) ....

Figure 1 Details of ethnicity categories presented to questionnaire respondents

Data analysis

We used model A to compare patient preferences for non-white ethnic-minority patients versus others (model 1), South Asian patients versus others (model 2), and female patients versus others (model 3). Y_{ij} is a binary dependent variable, from individuals i = 1...m, for observations j = 1...n_i. Observations n_i vary because the i individuals do not all complete every pairwise choice (some respondents do not answer all choices), μ_i is the random effects error term (which allows for multiple responses from i respondents), and ϵ_{ij} is the probit error term for individuals i for j observations. Variables are defined in the Materials and Methods section. D_s is a dummy variable and is equal to 1 if the respondent is in the subgroup, otherwise it is equal to 0.

$Y_i = \beta_0 + \beta_1 wait_{ij} + \beta_2 tissue_{ij} + \beta_3 dependant_{ij} + \beta_4 age_{ij} + \beta_5 disease1_{ij} + \beta_6 disease2_{ij} + \beta_7 ill1_{ij}$

$+ \beta_8 ill2_{ij} + \beta_9 D_s + \beta_{10} D_s wait_{ij} + \beta_{11} D_s tissue_{ij} + \beta_{12} D_s dependant_{ij} + \beta_{13} D_s age_{ij}$

$+ \beta_{14} D_s disease1_{ij} + \beta_{15} D_s disease2_{ij} + \beta_{16} D_s ill1_{ij} + \beta_{17} D_s ill2_{ij} + \mu_i + \epsilon_{ij}$

(Model A: models 1, 2 and 3)

Establishing the marginal rate of substitution (MRS)

MRS relates changes in attributes to a 1-year change in waiting time as a ratio. We used the Delta method (Wooldridge, 2002) to establish whether MRS was significant. This was because the binary dependent variable model that we used (random effects probit) was non-linear, and the Delta method can be used to establish confidence intervals for estimated parameters for these types of models (Greene, 2000). Moreover, the approach allows researchers to establish the significance or otherwise of a ratio of coefficients. Since MRS is a ratio, it allows clarification of whether MRS for a given variable is significant both for the defined subgroups of patients, and also for patients who are not in the defined ethnic specific or female subgroups (see Table 1). These tests for statistical significance were performed using the command 'nlcom' in STATA.

We also performed Wald tests to establish whether MRS in a subgroup differed in a statistically significant manner from MRS among other patients, in other words whether the non-white ethnic minorities, South Asian ethnic minorities or female subgroups had a different MRS to other patients who were not in that

Table 1 Calculation of MRS

Variable	Base group MRS	Variable	MRS for subgroup of respondents
Waiting time	N/A	Waiting time	N/A
Tissue	B_2/β_1	Tissue	$(\beta_2 + \beta_{11})/(\beta_1 + \beta_{10})$
Dependant	B_3/β_1	Dependant	$(\beta_3 + \beta_{12})/(\beta_1 + \beta_{10})$
Age	B_4/β_1	Age	$(\beta_4 + \beta_{13})/(\beta_1 + \beta_{10})$
Disease1	B_5/β_1	Disease1	$(\beta_5 + \beta_{14})/(\beta_1 + \beta_{10})$
Disease2	B_6/β_1	Disease2	$(\beta_6 + \beta_{15})/(\beta_1 + \beta_{10})$
Ill1	B_7/β_1	Ill1	$(\beta_7 + \beta_{16})/(\beta_1 + \beta_{10})$
Ill2	B_8/β_1	Ill2	$(\beta_8 + \beta_{17})/(\beta_1 + \beta_{10})$

N/A, not applicable.

subgroup. So, for example, in relation to the variable *tissue*, the test we conducted was whether $\beta_2/\beta_1 = (\beta_2 + \beta_{11})/(\beta_1 + \beta_{10})$. These tests were performed using the command 'testnl' in STATA. Wald tests establish whether there is a significant difference in MRS comparing MRS for base groups, versus defined subgroups for each attribute. Differences in MRS at the 5% level are indicated by P-values of ≤ 0.05.

Results

Sample characteristics

The UK National Kidney Federation, which publishes *Kidney Life*, could not provide us with data that might allow us to assess the representativeness of our sample, so instead we used data from the UK Renal Registry (Farrington *et al*, 2008a,b).

In total, 895 out of 908 respondents indicated their ethnic origin. Of these, 799 out of 895 patients (89.3%) were white (British), and 27 out of 908 (3%) were members of white ethnic minorities, so overall 92.3% of our sample was white. This compares with incidence data (Farrington *et al*, 2008a) which suggest that, across the UK, 79.8% of renal patients are white, so in our sample white patients were over-represented. Moreover, 69 out of 895 patients (7.7%) were members of non-white ethnic minorities, compared with a 17.9% incidence rate (Farrington *et al*, 2008a). Of the 69 members of non-white ethnic minorities, 50 patients were of South Asian origin. Therefore, 50 of the 895 patients in our sample (5.6%) were of South Asian origin, compared with a 10% incidence rate (Farrington *et al*, 2008a).

Members of non-white ethnic minorities consisted of two out of 69 mixed (white/black Caribbean), one out of 69 mixed (white/black African), one out of 69 mixed (white South Asian), two out of 69 with any other mixed background, including a Luso-Indian, one out of 69 Anglo-Indian/English-Portugese. In total, seven out of 69 were black or black British Caribbean, three out of 69 were black or black British (African), one out of 69 was black or black British (any other background), and two patients were Chinese.

The 50 South Asian patients in the non-white sample included 29 out of 69 South Asian or South Asian British (Indian) patients, nine out of 69 South Asian or South Asian British (Pakistani) patients, two out of 69 South Asian or South Asian British Bangladeshi patients, seven out of 69 South Asian or South Asian British (any other background) patients, plus one Filipina, one Persian and one Iranian patient.

In total, 508 out of 908 patients (55.9%) were male, 397 out of 908 patients (43.7%) were female, and three out of 908 patients (0.3%) did not indicate their gender. This is reassuring, as Renal Registry data that have been presented graphically (Farrington *et al*, 2008a) show a trend towards slightly higher proportions of men than women among renal patients for all age groups.

The average patient age was 54.88 years (median 57 years). For members of white ethnic minorites the average age was 55.65 years (median 57 years), for those belonging to non-white ethnic minorities it was 54.12 years (median 56 years), and for patients of South Asian origin it was 55.38 years (median 56.5 years). Among male patients (508/908) the average age was 56.49 years (median 58 years), and among female patients (397/908) it was 52.85 years (median 54 years). Unfortunately the Renal Registry data (Farrington *et al*, 2008b) are not specific for ethnic origin or gender. However, the median age for all patients is 56.9 years, which is remarkably close to our figure of 57 years.

The sample consisted of 468 out of 908 patients (51.5%) with successful transplants, 118 out of 908 patients (13%) whose transplant failed, and 279 out of 908 patients (30.7%) who were awaiting transplants, with an average waiting period of 22.6 months. Some patients whose transplant failed are also included in the data for those awaiting transplants. This also applies to all gender and ethnic-minority groups. A total of 237 out of 908 patients (26.3%) were on dialysis without transplantation, and 57 out of 908 patients (6.3%) had kidney disease that did not require dialysis. Renal Registry prevalence data (Farrington *et al*, 2008b) suggest that 46.6% of patients have successful transplants (as this is their current treatment modality), which is reassuringly close to our figure. However, there are no data for patients with failed transplants, or for those awaiting transplants, on dialysis without transplantation, or with kidney disease not requiring transplantation. Among non-white ethnic minorities there were 18 out of 69 patients (26%) with successful transplants, 10 out of 69 patients (14.5%) whose transplant failed, 35 out of 69 patients (50.7%) awaiting a transplant on dialysis (average waiting period 21.45 months), and three out of 69 patients (4.3%) with kidney disease not requiring dialysis. Among those of South Asian origin, 10 out of 50 patients (20%) had successful transplants, eight out of 50 patients (16%) had failed transplants, 28 out of 50 patients (56%) were awaiting transplants (average waiting period 23.1 months), and three out of 50 patients (6%) were on dialysis without transplantation. Unfortunately, the available data (Farrington *et al*, 2008b) were not analysed by ethnic origin. However, given the shortage of transplants available to ethnic-minority groups, and their lower success rates, because they are likely to be poorer tissue matches, the lower percentage figure for transplant successes and the higher percentage figure for transplant failures might be expected.

Data analysis

The results for models 1 to 3 are presented in Tables 2, 3 and 4.

Table 2 Model 1: patients – dummy variables for non-white ethnic-minority patients

Attribute	Coefficient excluding non-white ethnic minorities	MRS excluding non-white ethnic minorities	Coefficient for dummy variables for non-white ethnic minorities	MRS for non-white ethnic minorities	Wald test (*P*-value)
Waiting time	0.448**	1	–0.0025	1	
Tissue	0.690**	1.54** (1.19/1.89)	–0.0718**	–0.07 (–1.13/1.00)	< 0.001
Dependant	0.0605**	1.35** (1.08/1.62)	0.03450	2.26** (1.16/3.36)	0.311
Age	0.0074**	0.16** (0.13/0.20)	–0.0045	0.07 (–0.05/0.19)	< 0.001
Disease1	0.0067	0.15 (–0.90/1.21)	–0.0773	–1.67 (–5.55/2.21)	0.375
Disease2	0.7138**	15.93** (13.96/17.91)	–0.3649**	8.25** (2.86/13.64)	< 0.001
Ill1	–0.1113**	–2.48** (–1.16/–3.81)	–0.1049	–5.11* (–0.45/–9.78)	0.992
Ill2	0.1829**	4.08** (2.99/5.18)	0.0263	4.95* (0.97/8.92)	0.149
Intercepts	0.1306**		–0.0952		
Percentage of actual values predicted:	62.64%	Sample:	908 patients (69 are non-white ethnic minorities)	McFadden's R^2:	0.113
LR test (λ):	29.14	Dummy variables jointly significant?	Yes: CV for 9 dfs = 16.92	Log-likelihood:	–4987.2

* Denotes significance at 1% level.
** Denotes significance at 5% level but not at 1% level.

Table 3 Model 2: patients – dummy variables for South Asian patients

Attribute	Coefficient excluding South Asian ethnic minorities	MRS excluding South Asian ethnic minorities	Coefficient for South Asian ethnic minorities	MRS for South Asian ethnic minorities	Wald test (*P*-value)
Waiting time	0.0450**	1	–0.0069	1	
Tissue	0.0681**	1.51** (1.17/1.85)	–0.0824**	–0.38 (–1.74/0.99)	0.001
Dependant	0.0609**	1.36** (1.09/1.62)	0.0386	2.61** (1.07/4.16)	0.434
Age	0.0073**	0.16** (0.13/0.20)	–0.0055	0.048 (–0.11/0.21)	0.002
Disease1	0.0023	0.05 (–0.99/1.08)	–0.0243	–0.58 (–5.58/4.43)	0.803
Disease2	0.7095**	15.78** (13.84/17.71)	–0.4214**	7.57* (0.71/14.42)	< 0.001
Ill1	–0.1119**	–2.49** (–1.19/–3.80)	–0.1371	–6.54* (–0.42/–12.65)	0.827
Ill2	0.1807**	4.02** (2.94/5.10)	0.0785	6.81* (1.49/12.12)	0.417
Intercepts	0.1286**		–0.0932		
Percentage of actual values predicted:	62.71%	Sample:	908 patients (50 are South Asian ethnic minorities)	McFadden's R^2:	0.113
LR test (λ):	27.76	Dummy variables jointly significant?	Yes: CV for 9 dfs = 16.92	Log-likelihood:	–4987.85

* Denotes significance at 1% level.
** Denotes significance at 5% level but not at 1% level.

Non-white ethnic-minority patients vs. other patients

The likelihood ratio test for model 1 (see Table 2) is significant, which suggests that preferences do vary between members of non-white ethnic minorities and other patients. The Wald tests for three variables are also significant, which suggests that MRS differs significantly between the two patient groups for these three variables. For non-white ethnic minorities, MRS on the variable *tissue* is non-significant. This relates to prioritising recipients with a good tissue match, so members of non-white ethnic minorities would not prioritise to recipients with better tissue matches. For other patients it is positive and significant, implying a preference for prioritising recipients with better tissue matches. Another difference relates to age. Among members of non-white ethnic minorities the variable *age* is non-significant, so they would not prioritise younger recipients, whereas among other patients this variable is positive and significant, suggesting a preference for prioritising younger recipients. Finally, there is evidence that preferences vary in relation to prior-

itising those with diseases that affect life expectancy. The variable *disease2* relates to prioritising those with moderate rather than severe diseases that affect life expectancy. Members of non-white ethnic minorities place less emphasis than do other patients on prioritising those with moderate rather than severe diseases that affect life expectancy (MRS = 8.25 vs. 15.93).

South Asian patients vs. other patients

A similar pattern emerges in the South Asian patient sample (see Table 3), which is not unexpected, as they represented a large proportion (50 out of 69) of the non-white ethnic-minority group. Once again likelihood ratio tests suggest that preferences do vary between the two patient groups, and the Wald tests suggest that these differences relate to the same three variables. There is no evidence that South Asian patients would prioritise those with a better tissue match, as the variable *tissue* is non-significant. However, among other patients, the variable is positive and significant, which suggests a preference for prioritising recipients with better tissue matches. South Asian patients would

Table 4 Model 3: patients with female patient dummy variables

Attribute	Coefficient for male patients	MRS for male patients	Coefficient for female patients	MRS for female patients	Wald test (*P*-value)
Waiting time	0.0448**	1	–0.0003	1	
Tissue	0.0603**	1.34** (0.90/1.78)	0.0045	1.45** (0.95/1.96)	0.009
Dependant	0.0575**	1.28** (0.94/1.62)	0.0141	1.61** (1.20/2.01)	0.014
Age	0.0064**	0.14** (0.10/0.19)	0.0011	0.17** (0.11/0.22)	0.026
Disease1	–0.0373	–0.83 (–2.21/0.54)	0.0704	0.74 (–0.80/2.28)	0.137
Disease2	0.6917**	15.43** (12.91/17.93)	–0.0295	14.86** (12.07/17.64)	<0.001
Ill1	–0.1150**	–2.56** (–0.85/–4.27)	–0.0131	–2.87** (–0.94/–4.80)	0.285
Ill2	0.1615**	3.60** (2.19/5.01)	0.0520	4.79** (3.18/6.40)	0.175
Intercepts	0.1144**		0.0201		
Percentage of actual values predicted:	62.50%	Sample:	908 patients (397 are female)	McFadden's R^2:	0.110
LR test (λ):	5.00	Dummy variables jointly significant?	No: CV for 9 dfs = 16.92	Log-likelihood:	–4908.40

* Denotes significance at 1% level.
** Denotes significance at 5% level but not at 1% level.

not prioritise the young rather than the old, as the variable *age* is non-significant, whereas among other patients it is positive and significant. Finally, although both South Asian patients and the rest of the patient sample would prioritise those with moderate rather than severe diseases that affect life expectancy, South Asian patients would be less likely to prioritise on the basis of this criterion (MRS = 7.57 vs. 15.78).

Preferences and gender

The results of the likelihood ratio test do not provide evidence of a difference in preferences between male and female patients (see Table 4). However, Wald tests suggest that preferences may vary in relation to four out of eight variables. These tests suggest that preferences may vary in relation to prioritising on the basis of tissue match (*tissue*). Both male and female patients valued this criterion significantly. However, it appears that females value it marginally more than do males (MRS = 1.45 vs. 1.34). The Wald test also suggests that preferences differ with regard to prioritising recipients with child or adult dependants. The variable *dependant* is significant for both groups, but female patients appear to value this marginally more (MRS = 1.61 vs. 1.28). The Wald test suggests that preferences for prioritising younger rather than older dependants might

also differ. Female patients place marginally more emphasis on this variable (*age*) than do males (MRS = 0.17 vs. 0.14). Finally, both female and male patients value prioritising those with severe rather than moderate diseases that affect life expectancy (*disease2*) significantly. However, this variable seems to be valued marginally less by female patients (MRS = 14.86 vs. 15.43).

These findings suggest that patients who are not members of ethnic minorities value prioritising patients with closer tissue matches, whereas South Asian patients and those from non-white ethnic minorities do not. Patients in general, including those who belong to ethnic minorities, prioritise those who have had to wait a long time for a transplant, and those with child or adult dependants. However, prioritising younger people is not valued among South Asians and non-white ethnic minorities, whereas it is among other patients. Those with moderate rather than severe diseases that affect life expectancy are a priority for patients in general, but less of a priority among South Asian patients and non-white ethnic minorities. All ethnic groups value prioritising those with moderate as opposed to no diseases that affect quality of life. This may seem a somewhat odd result, but it could be explained by enlightened self-interest, in that many respondents themselves would have moderate diseases, in addition

to kidney disease, which affect their quality of life. More-over, there is no evidence that the ethnic-minority groups value prioritising those with moderate rather than severe diseases that affect quality of life differently. Both groups would prioritise potential recipients with moderate rather than severe diseases that affect quality of life.

Although there is evidence that preferences vary according to gender, these differences are not particu-larly pronounced. However, women do have a slightly greater tendency to prioritise recipients who are better tissue matches to donors. Women are also slightly more likely to prioritise those with child or adult depend-ants, and younger people, and slightly less likely to prioritise those with moderate rather than severe diseases that affect life expectancy.

Discussion

Discrete choice experiments (DCEs), sometimes re-ferred to as conjoint analysis (Ryan and Farrar, 2000), are increasingly used in health technology assessment (Ryan, 1999) and health economics (Ryan and Gerard, 2003). Indeed, searches on PubMed have identified several hundred health-related DCEs. However, although some DCEs have addressed the concerns of ethnic minorities (Bennett and Savani, 2004; Dwight-Johnson et al, 2004; Byrne et al, 2006; Hall et al, 2006; Peacock et al, 2006; Hawley et al, 2008; Sung-Jae et al, 2008; Constantinesgu et al, 2009), the majority have assessed preferences for respondents overall, rather than for minority groups. Only a very few DCEs have looked at gender-related issues (Brown et al, 2003; Mays and Zimet, 2004; Tsang et al, 2004; Kjaer et al, 2006; Hjelmgren and Anell, 2007; Gerard et al, 2008).

DCEs have strong theoretical foundations in econ-omics. They are compatible with Lancaster's charac-teristics theory of demand (Lancaster, 1966) and random utility theory (McFadden, 1999). They are often used to establish how much people are willing to pay for different attributes of healthcare provision. However, there are methodological issues which need to be addressed before it can be assumed that DCE estimates of willingness to pay (WTP) are accurate (Ryan et al, 1998; Ratcliffe, 2000b; Ryan and Farrar, 2000; Ryan et al, 2003). One major concern is that if they are applied in a context in which healthcare is free at the point of use, respondents may indicate an unreal-istically high WTP, because they know that they will not in fact bear a cost, leading to hypothetical bias. Alternatively, they may conceal WTP because they feel the question may be a precursor to the introduction of charging, leading to strategic bias.

We did not elicit WTP, thereby avoiding many of these problems. However, it must be conceded that our results are sensitive to the choice of attributes selected, and can only give an indication of trade-offs in relation to the actual attributes included. Since there are no definitive criteria for establishing the appropri-ate attributes and levels to include in a DCE, researchers simply have to consult a wide range of opinion, in-cluding patients and professionals, before deciding upon the attributes and levels, and ensure that the choice of attributes is defensible.

Although DCEs have been applied to determine priorities for liver transplants (Ratcliffe and Buxton, 1999; Ratcliffe, 2000a), that UK study did not collect ethnicity data, only gender data. The study reported differences in responses by gender, but the data were not analysed to establish whether preferences varied with gender. The only other DCE work in the area of transplantation is another UK study of factors that influence people's willingness to donate body parts for transplantation in the event of their death (Bennett and Savani, 2004). This considered three groups (white, South Asian and Afro-Caribbean), but concluded that 'being of a particular ethnicity or gender did not affect outcomes in any meaningful ways', so they only reported results for respondents overall (Bennett and Savani, 2004, p. 76).

In the field of transplantation there are of course other studies which do not use DCE methodology. Other kidney allocation studies were conducted in Australia and America (Louis et al, 1997; Browning and Thomas, 2001), and may not be generalisable to the UK. The Australian study (Browning and Thomas, 2001) involved 238 respondents ranking possible pri-ority criteria for transplantation, including age, gender, occupation, education, work status, income, whether potential recipients were parents, post-transplantation prognosis, and length of time for which recipients had been on the transplant list. They therefore avoided addressing the issue of whether to prioritise on the basis of ethnicity. They found that over 90% of 238 respondents considered that recipient gender, socio-economic status, employment status and occupation should not influence decisions about kidney trans-plant allocation. Instead, most of the respondents (87.4%) considered that those who had been on the transplant list for a long period of time should have priority, and 79% would prioritise those with a good prognosis, whilst 65% would prioritise younger recip-ients.

The American study (Louis et al, 1997) noted that the American point-based allocation system disadvan-taged African Americans because of its emphasis on antigen matching, as African Americans typically have a disproportionate number of rare antigens. They used semi-structured interviews with 33 patients who were awaiting transplants, including some black Americans who considered that discrimination in organ allocation by antigen matching was unfair. However, there was a

paradox in that they did not want to receive organs that gave them a reduced likelihood of survival. So these results differ from ours, but of course the rate of graft survival has increased since the American study because of improvements in anti-rejection drugs, so this may explain the differences in findings. The authors did not address the issue of gender-related differences.

There is one other study (Geddes *et al*, 2005), which was conducted in Scotland. A total of 295 respondents were asked to choose one of two hypothetical patients from eight scenarios to establish whether the patients agreed with the current criteria for transplant allocation in the UK. Ethnicity was not taken into consideration in this research, although gender was addressed. The findings suggested that neither age nor gender of the recipient should be used when making decisions about the allocation of kidneys. The latter finding is somewhat at odds with our findings for the non-ethnic-minority patients, who, unlike the ethnic minorities, would tend to prioritise younger recipients. This research was conducted prior to the UK Transplant 2006 reforms to transplant allocation criteria. It seemed to broadly support a shift away from the previous emphasis on tissue matching. It showed that only 24.6% of 295 respondents agreed with UK transplant policy at a time when the survival advantage of transplanting to a recipient whose transplant would be a closer match to the donor justified transplanting to a patient who had waited for only two years rather than seven years. The main conclusion was that allocation should favour respondents who had waited for longer, and of course UK transplant policy did evolve to place more emphasis on those who have waited a long time for a transplant.

Conclusions

Our findings are broadly supportive of revisions to UK transplant kidney allocation policy in 2006, which reduced the emphasis on transplanting to patients with good tissue matches. However, although the policy shift places less emphasis on tissue matching as an allocation criterion, current policy still retains quality of tissue matching as an allocation criterion. Although this might be supported by the majority of patients, evidence from this research suggests that it would not be supported by South Asians and members of non-white ethnic minorities more generally. Non-white ethnic minorities and South Asians would prefer the quality of tissue type matching between donor and recipient to be abandoned as a criterion for allocation. They are disadvantaged if transplant allocation is based on tissue matching, which no doubt accounts for this finding. UK Transplant's policy shift towards prioritising

those who have waited a long time for a transplant is supported by these findings for all ethnic-minority groups, irrespective of gender. However, the other shift in emphasis, towards prioritising younger patients, does not appear to be supported by ethnic-minoritiy groups, although it is supported by other patients. Although we have found some evidence that preferences do vary with gender, these differences are not particularly pronounced, which suggests that an attempt to facilitate the preferences of people according to gender is a low priority, and that addressing the specific needs and disadvantages of ethnic-minority groups should be a more urgent consideration when transplant policy is reassessed.

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REFERENCES

Bennett R and Savani S (2004) Factors influencing the willingness to donate body parts for transplantation. *Journal of Health and Social Policy* 18:61–85.

Brown AJ, Swinyard W and Ogle J (2003) Women in academic evidence: a report of focus groups and questionnaires, with conjoint analysis. *Journal of Women's Health* 12:999–1008.

Browning CJ and Thomas SA (2001) Community values and preferences in transplantation organ allocation decisions. *Social Science and Medicine* 52:853–61.

Byrne MM, Souchek J, Richardson M *et al* (2006) Racial/ethnic differences in preferences for total knee replacement surgery. *Journal of Clinical Epidemiology* 59:1078–86.

Churak JM (2005) Racial and ethnic disparities in renal transplantation. *Journal of the National Medical Association* 97:153–160.

Constantinesgu F, Goucher S, Weinstein A *et al* (2009) Understanding why rheumatoid arthritis patient treatment preferences differ by race. *Arthritis and Rheumatism* 61:413–18.

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

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

Dwight-Johnson M, Lagomasino IT, Aisenberg E *et al* (2004) Using conjoint analysis to assess depression treatment preferences among low-income Latinos. *Psychiatric Services* 55:934–6.

Farrington K, Udayaraj U, Glig J *et al* (2008a) ESRD incident rates in 2007 in the UK: national and centre-specific analyses. In: *UK Renal Registry 2008 Report*; www.renalreg.org (accessed April 2009).

Farrington K, Hodsman A, Casula A *et al* (2008b) ESRD prevalent rates in 2007 in the UK: national and centre-specific analyses. In: *UK Renal Registry 2008 Report*; www.renalreg.org (accessed April 2009).

Geddes CC, Rodger RS, Smith C *et al* (2005) Allocation of deceased donor kidneys for transplantation: opinions of patients with CKD. *American Journal of Kidney Diseases* 46:974–5.

Gerard K, Salisbury C, Street D *et al* (2008) Is fast access to general practice all that should matter? A discrete choice experiment of patients' preferences. *Journal of Health Services Research and Policy* 13(Suppl. 2):3–10.

Greene WH (2000) Functional form, nonlinearity and specification. In: *Econometric Analysis*. 4th edn. Upper Saddle River NJ: Prentice Hall International Incorporated.

Hall J, Fiebig DG, King MT *et al* (2006) What influences participation in genetic carrier testing? Results from a discrete choice experiment. *Journal of Health Economics* 25:520–37.

Hawley ST, Volk RJ, Krishnamurthy P *et al* (2008) Preferences for colorectal cancer screening among racially/ethnically diverse primary care patients. *Medical Care* 46(Suppl. 1):S5–9.

Higgins RM, West N, Edmumds ME *et al* (1997) Effect of a strict HLA matching policy on the distribution of cadaveric kidney transplants to Indo-South Asian and white European recipients: regional study. *BMJ* 315:1354–5.

Hjelmgren J and Anell A (2007) Population preferences and choice of primary care models: a discrete choice experiment in Sweden. *Health Policy* 83:314–22.

Kjaer T, Gyrd-Hansen D and Willaing I (2006) Investigating patients' preferences for cardiac rehabilitation in Denmark. *International Journal of Technology Assessment in Health Care* 22:211–18.

Koene RA (2002) Should the allocation of cadaveric kidneys for transplantation be based on HLA matching? *Nephrology Dialysis Transplantation* 17:717–18.

Lancaster KJ (1966) A new approach to consumer theory. *Journal of Political Economy* 74:132–57.

Louis ON, Sanker P and Ubel PA (1997) Kidney transplantion candidates' views of the transplant allocation system. *Journal of General Internal Medicine* 12:478–84.

McFadden D (1999) Computing willingness-to-pay in random utility models. In: Melvin JR, Moore JC and Riezman R (eds) *Trade, Theory and Econometrics: essays in honor of John S Chipman*. Abingdon: Routledge. pp. 253–74.

Mays RM and Zimet GD (2004) Recommending STI vaccination to parents of adolescents: the attributes of nurse practitioners. *Sexually Transmitted Diseases* 31:428–32.

Peacock S, Apicella C, Andrews L *et al* (2006) A discrete choice experiment of preferences for genetic counselling among Jewish women seeking cancer genetics services. *British Journal of Cancer* 95:1448–53.

Raleigh VS (1997) Diabetes and hypertension in Britain's ethnic minorities: implications for the future of renal services. *BMJ* 314:209–12.

Ratcliffe J (2000a) Public preferences for the allocation of donor liver grafts for transplantation. *Health Economics* 9:137–48.

Ratcliffe J (2000b) The use of conjoint analysis to elicit willingness-to-pay values. Proceed with caution? *International Journal of Technology Assessment in Health Care* 16: 270–5.

Ratcliffe J and Buxton M (1999) Patients' preferences regarding the process and outcomes of life-saving technology. *International Journal of Technology Assessment in Health Care* 15:340–51.

Ryan M (1999) A role for conjoint analysis in technology assessment in health care? *International Journal of Technology Assessment in Health Care* 15:443–57.

Ryan M and Farrar S (2000) Using conjoint analysis to elicit preferences for health care. *BMJ* 320:1530–33.

Ryan M and Gerard K (2003) Using discrete choice experiments to value health care programmes: current practice and future research reflections. *Applied Health Economics and Health Policy* 2:55–64.

Ryan M, McIntosh E and Shackley P (1998) Methodological issues in the application of conjoint analysis in healthcare. *Health Economics* 7:373–8.

Ryan M, Watson V and Amaya-Amaya M (2003) Methodological issues in the monetary valuation of benefits in healthcare. *Expert Review of Pharmacoeconomics* 3: 717–27.

Street DJ, Burgess L and Louviere J (2005) Quick and easy choice sets: constructing optimal and nearly optimal stated choice experiments. *International Journal of Research Marketing* 22:459–70.

Sung-Jae L, Brooks RA, Newman PA *et al* (2008) HIV vaccine acceptability among immigrant Thai residents in Los Angeles: a mixed-method approach. *AIDS Care* 20:1161–8.

Tsang HW, Chan F and Chan CC (2004) Factors influencing occupational therapy students' attitudes towards persons with disabilities: a conjoint analysis. *American Journal of Occupational Therapy* 58:426–34.

UK Transplant (2006) *Transplant Activity in the UK*. Bristol: Statistics and Audit Directorate.

Wooldridge JM (2002) *Econometric Analysis of Cross Section and Panel Data*. Cambridge, MA: MIT Press.

CONFLICTS OF INTEREST

None.

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