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A note on a discussion group study of public preferences regarding priorities in the allocation of donor kidneys

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Abstract

Objective: To explore whether and how people wish to give differential priority based on certain characteristics of the potential recipient of a donor kidney. *Design:* A random sample of people resident in York was invited to attend two focus group meetings each, a fortnight apart. *Setting:* The City of York. *Participants:* Twenty-three randomly chosen people meeting in four groups of five or six. *Main outcome measures:* Those factors that people think should be taken into account when allocating donor kidneys, in addition to the expected benefits from transplantation. *Results:* People are willing and able to distinguish between potential recipients of a kidney transplantation according to a range of characteristics beyond the expected benefits from treatment. There is a clear consensus across the four groups that one of the most important considerations is what will happen to the patient without treatment, and so priority is given to those with a poor prognosis. There is also a strong view that priority should be given to younger patients and to those with dependants. The time spent waiting for a transplant is also important, but less so. *Conclusions:* A sample of the general public, after discussion and debate, wish to take account of a number of patient characteristics when allocating donor kidneys. There is some degree of consensus about what these factors should be and this suggests that it might be possible to develop a set of guidelines for the allocation of donor kidneys.
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1. Introduction

Approximately 30,000 people in the UK have chronic renal failure. There are about 1750 kidney transplantations carried out each year. This means that a great many people who are currently on renal dialysis will die before they have the chance of a

transplant. The Kidney Advisory Group has developed a number of allocation rules to determine who receives an offer when an organ becomes available. These rules operate on a points system and take into account histocompatability, blood group, age, clinical need, waiting time, matchability and sensitisation (http://www.uktransplant.org.uk). The World Health Organisation has stated that "donated organs should be made available to patients on the basis of medical need and not on the basis of financial or other considerations" [1]. Similarly, the American Medical

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Association has deemed that a person's ability to pay, their contribution to society, the cause of their condition and their past use of medical resources are all unacceptable grounds on which to discriminate against patients requiring a kidney transplant [2].

However, these decisions are made solely within the professional transplant community and do not take into account the views of the general public. A number of recent studies in the context of allocating donor livers suggest that the general public do not fully share these values. In two studies in the US, Ubel and Loewenstein [3,4] asked members of the general public to distribute livers among patients with varying chances of successful outcome. They found that, in addition to prognosis, respondents took account of the family commitments they had and the time they had spent waiting for a transplant, and that they were also concerned about giving everyone a chance. In the UK, Ratcliffe [5] found that the majority of a convenience sample of university staff wished to give priority to patients with naturally occurring (as opposed to alcoholic) liver disease, to younger patients, and to those who have been waiting longest. Similarly, Neuberger et al. [6] found from interviews with the UK general public that prognosis, age and time on the waiting list were the three most important factors in selecting recipients for transplantation.

There have been other studies across a range of different contexts which have demonstrated a broadly similar set of public preferences; that is, to discriminate in favour of the young and those with dependants, and to discriminate against those who are considered to be in some way responsible for their ill health [7,8]. However, we are not aware of any studies that have looked specifically at kidney transplantation. Moreover, the evidence currently available has been generated mainly from surveys which means that we cannot really appreciate how respondents are interpreting the questions asked of them. In addition, it has been shown that people's preferences can change after a period of discussion and deliberation [9] and it is arguably these more considered preferences that should be used to inform public policy [10].

In this study, focus group discussions were convened in order to allow us to gain insights into the cognitive processes that respondents use when discussing how to allocate donor kidneys. Such discussions allow the respondents the time and opportunity to discuss the issues and to deliberate over their responses. The study was specifically designed to explore whether and how people wish to give differential priority based on certain personal characteristics of the potential recipient of a donor kidney.

2. Methods

The sample (see Table 1) was recruited by a York-based agency who were instructed to recruit four groups of six people, with three men and three women in each group and one person from each of the six age groups shown in Table 1. As can be seen from the table, one young man failed to turn up in Group 3. The respondents attended two group meetings at a hotel in York. Each meeting lasted for about 2 h with 2 weeks between each meeting. The respondents were paid £30 for attending both meetings.

In the first meeting, respondents were introduced to the idea of priority-setting in health care and, in very general terms, asked to discuss how they might determine priorities on waiting lists for elective surgery and a general medical check-up. These general scenarios were designed to encourage them to discuss general rationing issues with one another. Respondents were then presented with the kidney scenarios that are of relevance here. They were given information about how many and what types of people have chronic renal failure, how many transplants there are each year and a general description of what life would be like on dialysis. They were then asked the question "What factors do you think should be taken into account when deciding who gets an organ?"

At the beginning of the second meeting, respondents were given a much more specific task, which is summarised in Table 2. They were asked to think of themselves as members of an advisory committee that would decide how to allocate a donor kidney. They were initially presented with information relating to six patient's prospects (in terms of life expectancy) with and without a kidney transplant. They were told that each was an equally good match for the kidney and were asked to choose which patient should get it. They were told—and reminded—that each patient has only this one chance of a transplant. After respondents had decided which patient they would give the kidney to, they were provided with additional information re-

Table 1
Characteristics of the 23 respondents

	Total (%)	Group 1	Group 2	Group 3	Group 4
Male	11 (48)	3	3	2	3
Female	12 (52)	3	3	3	3
Age					
18–24	3 (13)	1	1	0	1
25–34	4 (17)	1	1	1	1
35–44	4 (17)	1	1	1	1
45–54	4 (17)	1	1	1	1
55–64	4 (17)	1	1	1	1
>65	4 (17)	1	1	1	1
Smoker	4 (17)	1	1	1	1
Non-smoker	19 (83)	5	5	4	5
Minimum education[a]	13 (57)	3	3	4	3
Stayed on	10 (43)	3	3	1	3
Private health insurance	3 (13)	1	1	0	1
No private insurance	20 (87)	5	5	5	5
Employed	14 (61)	4	3	4	3
Other	9 (39)	2	3	1	3
Limiting long-term illness	3 (13)	1	2	0	0
No limiting long-term illness	20 (87)	5	4	5	6

[a] This would have been 15 years of age for respondents in the two oldest age groups (>55) and 16 for all other respondents.

lating to the ages of the six patients, and were asked whether they wanted to revise their answer. Finally, it was revealed to them that the six patients were in fact the six (or in one case, five) group members (the ages of the respondents were rounded up or down slightly for comparability across the groups).

All groups were convened and moderated by both authors. The moderators initially allowed respondents to set the priorities in their own language and frameworks of understanding but, as the discussion progressed, probed respondents to elicit further details and to highlight any differences of opinion between respondents. All group discussions were tape-recorded and transcribed verbatim. The transcripts were then analysed using a variant of grounded theory [11]. This took the form of creating an index system of the factors respondents mentioned by coding the relevant sections of the transcripts on a sentence-by-sentence basis and applying appropriate labels (i.e. 'age', 'family responsibilities'). Once a factor had been identified

Table 2
Table used to ask respondents to choose which patient should get the kidney

Patient	Additional life expectancy without transplant	Additional life expectancy with transplant	Years added by treatment	Age	Group participant[a]
A	16	46	30	20	
B	13	38	25	25	
C	10	30	20	35	
D	7	22	15	45	
E	4	14	10	50	
F	1	6	5	70	

[a] The name of the appropriate member of the discussion group was inserted here after the information in the other columns had been discussed.

and indexed, further examples were coded and added to the index only if they extended its meaning. All codings were checked and agreed upon by both authors.

3. Results

The responses to the question asked in the first meeting, about which factors should be taken into account when allocating donor kidneys showed little variation across the four groups, as shown in Table 3. Respondents wanted to take into account a number of factors other than the capacity to benefit from treatment. These factors were, in the order mentioned, what will happen without treatment, age, family responsibilities, waiting time, the cause of ill health and whether the treatment is a re-transplantation.

For all four groups, the benefit from organ transplantation was the most important criterion. This was discussed in terms of benefits in quality of life and increases in length of life. Respondents did not really discuss the variation in benefits from transplantation and made no reference to how to the best ways of ensuring that benefits were maximised (e.g. by a kidney sharing alliance [12]). The discussion of the benefits of a transplant led naturally into a discussion of what life would be like on dialysis, again discussed in general quality of life and length of life terms.

Every respondent except one wanted to prioritise younger over older patients and this involved focusing on both ends of the age spectrum, e.g. "They have all their lives in front of them" and "A 70-year-old has had his life, he's had the chance to live". Most respondents favoured saving the lives of the younger person because they have had a shorter life, although one

noted that the youngest would live longer and benefit more. Respondents in all groups felt that whether or not a person had responsibilities, particularly in caring for children, should be taken into account, e.g. "If it's a woman who's got five children then it'll affect the children as well but if its just one person, I mean its still awful, just awful, but it's a fact of life, y'know".

The question of health related behaviours provoked discussion and dissent. In the general discussion about priority-setting, some respondents were very in favour of discriminating against those with self-inflicted illness, others were very against, voicing concern about how to decide when a behaviour is freely chosen. However, in the context of donor transplantation, when having to make a choice between two individuals, respondents often chose the person whose kidney failure is not self-inflicted e.g. "I would think that if there were two people exactly the same age, the same sort of condition, same match, but one had kidney failure because of natural circumstances and one had kidney failure because of being in a night club and taking ecstasy, I would be tempted to give it to the first person".

The same kinds of argument were repeated in response to the more specific task at the beginning of the second group meeting. Using group 1 as an example, when presented with information on life expectancy with and without the transplant, four respondents chose to allocate the donor kidney to patient A and two chose patient F. The additional information relating to the ages of the six patients, reinforced the feelings of one respondent who stated: "Definitely A again now. The 70-year-old has lived his life", but caused two to revise their answers, choosing instead patient C: "The chances of A having children at the age of 20 are slight, but the 35-year-old probably does

Table 3

Responses to the question "What factors do you think should be taken into account when deciding who gets an organ?" in the order they were mentioned

	Group 1	Group 2	Group 3	Group 4
1	Benefit from treatment	Benefit from treatment	Benefit from treatment	Benefit from treatment
2	What will happen without treatment	What will happen without treatment	What will happen without treatment	What will happen without treatment
3	Family responsibilities	Family responsibilities	Age	Age
4	Age	Age	Waiting time	Family responsibilities
5	Waiting time	Waiting time	Family responsibilities	Cause
6	Retransplantation	Cause		Waiting time
7	Cause			Retransplantation

Table 4
Results from the question in Table 2, showing how responses may have changed as additional information was provided

	Additional life expectancy with and without transplant	Age	Group participant
Group 1	Four chose patient A Two chose patient F	Four chose patient A Two chose patient C	Four chose youngest group member Two chose group member with dependants
Group 2	Three chose patient A Three chose patient F	Five chose patient A One chose patient C	Three chose youngest group member Three chose group member with dependants
Group 3	Three chose patient A Two chose patient F	Four chose patient A One chose patient C	Four chose youngest group member One chose group member with dependants
Group 4	Five chose patient A One chose patient F	Four chose patient A Two chose patient C	Four chose youngest group member Two chose group member with dependants

have children". When it was finally revealed that the six patients were in fact the six group members, four still chose patient A, but now two chose patient B because this group member had children. Table 4 shows very similar results to this task across all four groups.

4. Discussion

The sample of members of the general public were willing and able to discriminate between the potential recipients of a kidney transplant according to a range of characteristics beyond the expected benefits from treatment. Respondents often put themselves into the position of patient awaiting a kidney and often disclosed personal information. A number actively facilitated the discussion, offering hypothetical situations for debate. The more specific discussion at the beginning of the second group meeting therefore quickly became very personalised—not in a confrontational way but rather in a way which allowed respondents to really participate in the exercise.

The groups discussed many questions relating to how to determine priorities in the allocation of donor kidneys. Should younger patients be given more priority than older ones? Should those with children be given a higher priority than those without children? Should those whose illnesses are deemed to be self-inflicted be given less priority than others? After discussion and debate, the majority of respondents answered "yes" to each of these questions. Respondents also favoured taking account of how long a patient had been waiting for a transplant. These results sup-

port those found in the context of liver transplantation [3–6] and suggest that a similar set of personal characteristics might be relevant to organ transplantation generally.

At least, they suggest a similar set of characteristics in the context of a group discussion, and we cannot be sure that the same results would have been obtained from face-to-face interviews or a postal questionnaire. There is the danger in this study that some respondents may have given responses that they thought the researchers or other group members wanted to hear, rather than their 'true' preferences [13]. We certainly cannot dismiss this possibility but many people did mention the cause of the need for a transplant, which is a controversial issue and generated much heated discussion.

We have made no claims in this paper about the extent of the role that public preferences should play in the resource allocation process, and we did not ask our respondents to consider this issue either. We would argue, however, that public preferences should play some role and that, in the very least, policy-makers should be made aware of the public's preferences. If the results reported here, and especially the broad consensus across the groups, were to be repeated on a large sample, then the general public might well be in favour of a set of guidelines, or possibly a points-scheme, for allocating donor kidneys. Were such guidelines to be developed for micro level priority setting, the results presented here suggest that they would differentiate between individuals on the basis of a relevant personal characteristics and reward who have waited a long time [14,15].

A point-scheme might improve consistency in the allocation of donor kidneys but would doubtless receive opposition from some clinicians who would see it as a threat to their clinical freedom. The discussion of such issues is beyond the scope of the present paper, but we strongly suggest that future research should consider how best to simultaneously weight the range of relevant factors that go into the decision about who gets priority in kidney allocation decisions.

Acknowledgements

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