

Principles of distributive justice used by members of the general public in the allocation of donor liver grafts for transplantation: a qualitative study

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Abstract

Objective To investigate the nature of public preferences in the allocation of donor liver grafts for transplantation.

Design A qualitative study based upon the transcripts of four focus groups.

Setting Derby, Derbyshire, UK.

Participants Twenty-two members of the public in the Derby locality, recruited to one of four focus groups through local community groups.

Main outcome measures The views of focus group members as to the importance (or otherwise) of several potential discriminating factors which could be used in the prioritization of patients on the waiting list for liver transplantation were ascertained. The factors included were expected post-transplant prognosis, the age of the patient, whether the patient was personally responsible for their illness, the time spent on the waiting list, re-transplantation or primary transplant and the social background of the patient.

Results and conclusions Group members explored the criteria from a number of perspectives, and made some unexpected linkages between the criteria and wider moral principles. They did not come to firm conclusions about the relative desirability of the criteria, but their approach was notably flexible and thoughtful, with the exception of a few instances where they appeared to resort to arguments based on what is 'obvious' and 'natural'. The results of these discussions suggest that members of the public would be able and willing to respond positively to a more open and consultative system of donor liver prioritization than exists presently within the UK.

Background

Despite greater use of split livers (two liver grafts from one donor) and livers from marginal donors (e.g. non-heart beating donors or those

aged over 60 years), the supply of donor liver grafts for transplantation in the UK has remained relatively constant.¹ However, every year more patients are referred for liver transplantation, resulting in an increase in the waiting

list. Given this imbalance in demand and supply, decision criteria have necessarily to be employed to determine which patients should be given priority in receiving a donor organ. Unlike the US, the UK has no explicit guidelines for the allocation of donor liver grafts. In general, however, the length of time spent on the waiting list is used as the main criterion for donor liver allocation within the UK.²

In recent years the involvement of the public in rationing and prioritizing issues in health-care has been a focus of considerable interest, in terms of methods of data-collection,³ content of public views,⁴ and the validity of those views.⁵ Donor liver allocation is part of this picture, both nationally and internationally. Within the US in particular there has been and continues to be strong public debate regarding the guidelines which are used for the allocation of donor liver grafts.^{6,7} Within the UK, it is now becoming more widely accepted by decision makers that some form of public involvement in the process is of value in informing the evidential base upon which a more explicit system of donor liver graft allocation would be based.⁸

Several quantitative surveys of the general public's allocation decisions in liver transplantation have appeared recently within the health-care literature.⁸⁻¹¹ These surveys have suggested that public preferences may differ quite markedly from the established health economics view that scarce resources should be allocated (within a given budget constraint) so as to maximize health related quality of life. A common theme emerging from these surveys is the conclusion that members of the general public would be willing to exchange an overall reduction in the efficiency of the transplantation system, as defined by the maximization of health related quality of life, for a 'fairer' or more 'equitable' distribution of donor organs for transplantation.

However, this conclusion begs several questions. 'What would a fairer or more equitable system of donor liver graft allocation look like in the eyes of the general public?' 'What criteria may be used to discriminate amongst competing individuals on the liver transplant waiting list and how should such criteria be invoked?'

Five main potential discriminating criteria feature frequently in the literature on the debate on this issue, namely:

- (a) Expected prognosis following the operation;
- (b) Age of the patient;
- (c) Whether the patient can be considered to be personally responsible for their illness, e.g. through alcoholic liver disease (ALD);
- (d) Length of time spent on the waiting list;
- (e) Whether the patient is being transplanted for the first time or is being re-transplanted.

Expected prognosis following the operation

This criterion expresses in its most immediate form one of the major principles of distributive justice in health-care, that of utility. This in turn represents the utilitarian tradition of ethics. It also reflects the established health economics view that efficiency in achieving health gain is the most important criterion in the allocation of scarce health-care resources.

Age of the patient

This criterion has been shown to be important in previous quantitative studies addressing priority setting issues in health-care, with the most common conclusion being that there should be positive discrimination in favour of the young.¹¹⁻¹⁴ However, the majority of previous studies have failed to distinguish between reasons for age discrimination based on the principle of equity and those based on the principle of efficiency (given that young people will live longer and hence more health will be gained relative to older people). This study provides an occasion to establish the reasoning behind age discrimination.

Whether the patient can be considered to be personally responsible for their illness, e.g. through alcoholic liver disease

The ALD is the most common indication for liver transplantation in the UK. In addition the trend is increasing implying that greater numbers of

ALD patients will be referred to transplant units in the future.¹⁵ Some commentators have suggested that patients with ALD are personally responsible for their illness and should not be given the same priority as patients who have acquired liver disease through no fault of their own.⁶ The principle of distributive justice underlying this argument is that of desert, which focuses on the question of whether or not the patient who is responsible for their own disease deserves a transplant as much as the patient who is not.

Length of time spent on the waiting list

This criterion is already used to determine priority for liver transplantation in the UK.² It reflects a principle of equal entitlement through equal waiting which legitimizes the tradition of rationing by waiting list in the UK. This offers a way of highlighting the distributive justice principle of equity, making it available in a familiar form for informants to apply if they so choose.

Whether the patient is being transplanted for the first time or is being re-transplanted

This criterion allows another way for the principle of equity, in this case relating to the number of transplants allocated to each person, to be set against other principles such as need and entitlement.

All of the quantitative surveys undertaken to date have used a similar methodology, whereby hypothetical choice contexts have been used to elicit informants' preferences for the allocation of donor organs either to named individuals or more commonly to groups of individuals with particular characteristics. Although empirical data is important in this context, its usefulness is limited because it does not allow the investigator to identify the way informants explain and justify their particular choices. There is evidence that the public change their views about priority setting in health-care as a result of discussion and deliberation.¹⁶ However, the methodology used in quantitative surveys typically does not allow informants the opportunity to reflect upon and explain the thinking behind their preferences.

Study design

This study used qualitative research techniques to investigate the nature of public preferences in the allocation of donor liver grafts. The principle aim of the study was to inform the results of a previous quantitative survey undertaken by Ratcliffe,¹¹ facilitating an in-depth understanding of the arguments and explanations used by informants in determining and justifying allocation decisions for transplantation and the ethical and moral arguments expressed. The study was undertaken using four focus groups comprising members of the public in a predominantly white middle-class district of Derby, UK. They were recruited from local community groups, including Women's Institute branches, Parent-Teachers Associations and an over 60s group. Recruitment sought to maximize group homogeneity (a goal recommended by Krueger¹⁷) and also sought a reasonable age spread between groups. No health-related or transplant-related groups were approached, as the aim was to involve people without a specific prior interest in or knowledge of the issue.

The area was chosen for its accessible network of local groups and activities, and the profile of the groups reflected the socioeconomic, gender and age profiles of the area, and of the groups used to recruit. In particular the participants were white and predominantly middle-class. The youngest group had a 30–49 age range, and the oldest a 70–79 range. Both these groups were of mixed gender (the oldest was mainly male). The other two groups were intermediate in age, and all-female. The youngest group and one of the intermediate groups had six members each, and the other two groups had five members each. The sessions were facilitated by the researchers, JR and SW. Discussions were recorded, the recordings transcribed, and the transcripts analysed. A third colleague, external to the data gathering but with experience in qualitative data analysis, independently analysed the data to validate the researchers' analysis. The methods of analysis were based on the grounded theory model of identification of codes and themes,¹⁸ but were template-based in accordance with the

focus of the study.¹⁹ The main focus was on the content of the group discussion, although a separate written record of group process was kept, and referred to.

The purpose of the group discussion was to encourage informants to use the five criteria discussed above – expected prognosis following the operation, age of the patient, patient's responsibility for their illness, length of time spent on the waiting list, and whether the patient is being transplanted for the first time or is being re-transplanted – in the prioritisation of patients on the waiting list for liver transplantation. In the case of each criterion the main concern was to enable informants to explain their reactions, not simply to state them.

Each group was provided with a hypothetical case study which contained written descriptions of the characteristics of five individuals waiting for a liver transplant. The groups were told that all of these individuals were in urgent need of the transplant and would die within a few weeks if the transplants were not made available to them. However, only one donor liver was currently available which would match any of the individuals on the list. For the first part of the exercise (Appendix 1), the characteristics of the individuals concerned were based upon the criteria (a) to (e) previously described. In the second part of the exercise (Appendix 2), the focus group members were provided with more information relating to the social background of the individuals concerned in order to explore the extent to which this additional information would impact upon their views regarding priority for transplantation.

Results

Response to criteria

Expected prognosis following operation

The expected prognosis following the liver transplant operation caused the least moral discomfort as a criterion for differentiating between patients on the waiting list and was considered to be highly important by all four

focus groups. In general it was felt that the greater the life expectancy post-transplant the greater the priority for transplantation.

Some focus group members commented that the difference in survival times between the individuals, although significant in general, was not as important to them within the context of this exercise because the lowest level of survival (5 years) would still be quite significant to the individual/s concerned:

'Well the minimum is 5 years isn't it? I mean 5 years is not much, but in the context of dying now, it's a substantial choice isn't it, whatever your age.' (Ruth, age 47, social worker, youngest, mixed group)

However, the three younger groups also argued that time is not simply experienced quantitatively, and that 15 years is not necessarily three times as good as 5 years:

'those 5 years are very precious aren't they'. (Ellen, age 61, retired teacher, smaller intermediate all-female group)

The oldest, mainly male group and the smaller of the intermediate groups discussed life years as relative time as well as absolute time – so although 5 years may seem limited compared with 15 years, it is much better than 3 years or 1 year:

'lets forget the 5 years and just consider that he is going to live 1 year, whereas the other chap is going to live three, in that ratio, so it might be 10 years and 30 years ...' (Ray, age 71, retired policeman, oldest, mainly male group)

Although quality of life was not included specifically within the profile descriptions, all focus groups raised the question of the quality of survival post-transplant independently. The youngest, mixed group considered this issue at length and concluded that the quality of life experienced was an important criterion which needed to be balanced against the expected length of survival following the transplant:

'And having had a transplant, your quality of life has got to be improved and you can make the most of what you have got left, be it 5 years, 10 years, 15 years or whatever. I mean as far as each and every one of them is concerned, I mean life

expectancy is not final, you've got to make the best use of what you have got.' (Jo, age 38, Teacher, youngest, mixed group)

Whilst it was recognized that interpersonal comparisons were inevitable, the difficulties of measuring and interpreting quality of life were also remarked upon. Judgements of quality of life were seen as highly problematic:

'Yes I think all of us would resist the idea of somebody else making judgements about our quality of life and I think that's just natural that you would do that.' (Ruth, age 47, social worker, youngest, mixed group)

'I suppose it's like saying that we have got a better life, a better standard of life than somebody in a wheelchair, yet they would argue that their standard of life is just as good as ours.' (Tracy, age 30, confectioner, youngest, mixed group)

Age of the patient

The significance of age was interpreted in two main ways. The majority of focus group members felt quite strongly that age should not be a discriminatory factor except in a situation where it would have some impact upon the expected prognosis following the operation:

'Everyone should have the right to treatment, and age really, in my mind, shouldn't come into it unless there are other factors ... they perhaps have a dicky heart or some other disease.' (Phil, age 49, policeman, youngest, mixed group)

A minority thought that age was an important criterion and expressed a preference to differentiate in favour of the younger individuals in the exercise. The reasoning behind this argument in most cases was expressed in terms of an equity criterion on the basis of the 'fair innings' argument – that the older individual has already had the benefit of more years of life than the younger individual:

'The person who is 60 (Tom) he has already lived 20 years longer than the person who is 40, so they have had 20 years more life than the 40 years old.' (Gill, age 53, retired teacher, smaller intermediate all-female group)

'Tom would not be high on my list ... because he is 60 ... he has had a good do, he has obviously had a good life, let the young ones have a go.' (Tracy, age 30, confectioner, youngest, mixed group)

However, the oldest, mainly male group were an exception to this, in that some members saw age as an adjunct to prognosis, and its significance very much in terms of efficiency:

'The reason that age has got a hefty allowance to it is that really we can't get away from the fact that a younger person will be likely to make more use of the liver than an older person. But really the only reasons I have done it with age is as a kind of booster to length of survival.' (Ray, age 71, retired policeman, oldest, mainly male group)

There was a general feeling in the other three groups that discrimination on the basis of age *per se* (an equity criterion) would only become important if the age differences between the individuals were more pronounced:

'I have great difficulty between 40 and 60. I don't feel that one has more right than the other, not really.' (Julia, age 51, orthoptist, larger intermediate all-female group)

The difference seemed too narrow and members of the three younger groups wanted constantly to widen it, and talk about children and 80-year olds. The oldest, mainly male group also put children in a special category but did not identify the elderly as a separate age-band in the same way:

'I mean the natural thing is that you think a child should be given a chance because they are a child and they need a chance to grow.' (Miriam, age 46, psychiatric nurse, youngest, mixed group)

'I would have thought that children ought to be in a separate category.' (Ellen, age 61, retired teacher, smaller intermediate all-female group)

'84 is a bit different to 60, because you are nearly at the popping off stage anyway.' (Julia, age 51, orthoptist, larger intermediate all-female group)

There was also an instance of age being viewed as an index of accumulated merit:

'He has looked after himself, he has got to 60, he hasn't had any drinking problems or for that matter anything else, and I don't see why he should be counted out.' (Morag, age 59, housewife, larger intermediate all-female group)

Whether the patient can be considered to be personally responsible for their illness, e.g. through alcoholic liver disease

On the matter of responsibility, five positions emerged. (On occasion, one member articulated different positions at different times).

(i) That the alcohol-induced liver failure is the responsibility of that patient and they should 'carry the can' by going to the back of the queue:

'If people who drink know what it does they should face the consequences.' (Tracy, age 30, confectioner, youngest, mixed group)

(ii) That giving a liver to such a patient would be a waste because they will return to alcohol abuse – its in their nature:

'that person has a susceptibility to drink'. (Gill, aged 53, retired teacher, smaller intermediate all-female group)

(iii) Alcoholism is an illness, not a moral failing, and people should not be made to suffer for it:

'I mean alcoholism is just as much a disease as hepatitis if you like.' (Maureen, age 55, clerical officer, larger intermediate all-female group)

(iv) We should accept those who abuse their liver and treat them as equals on the basis of common humanity or equality of worth:

'nobody's perfect and everybody has a chance to make amends, I think these two probably above the others.' (Maisie, age 65, retired, smaller intermediate all-female group)

'My next instinctive reaction to it is to think I need to get past that (the alcoholism) and think it's about you know their value as individuals.' (Ruth, age 47, social worker, youngest, mixed group)

(v) We should reward, or recognize the virtue of, those who show the commitment to give up alcohol, by including them as candidates for transplant.

'I think if you have somebody that has tried and given up, you know, I think he or she should stand as good a chance as anyone else.' (Maureen, age 55, clerical officer, larger intermediate all-female group)

Length of time spent on the waiting list

In two focus groups the length of time already spent on the waiting list was seen as an 'automatic' criterion invoking a mechanistic process which helped to avoid making difficult decisions:

'I mean if ... the only criteria you have is who has been on the waiting list the longest then it is very easy, you don't have to make any other decision at all do you. You just look at Jayne who has been on the waiting list for 12 months, and Tom who has only been on for 3 months, so we will give it to Jayne and that is it and so it's much easier isn't it?' (Gill, age 53, retired teacher, larger intermediate all-female group)

'But it is very fair isn't it ... in a sense what they do now ... because nobody is making any judgement.' (Ellen, age 61, retired teacher, smaller intermediate all-female group)

The time spent on the waiting list was also perceived as a culturally acceptable phenomenon:

'Well the waiting list is normal for our country because we queue for most things.' (Ellen, age 61, retired teacher, smaller intermediate all-female group)

However, in the youngest group there was suspicion that time spent on the waiting list potentially disguised manipulations and massaging:

'I am a bit suspicious about the idea of waiting lists anyway because in a sense they can be massaged ... clinicians can say "yes I will put you on the waiting list because I know you are going to have to wait a long time so I will put you on now". Somebody who is maybe more urgent may not be put on until a later time.' (Ruth, age 47, social worker, youngest, mixed group)

Whilst in the oldest, mainly male group the cultural acceptability of this criterion was questioned. It was argued that liver transplantation was too important a procedure for the simple queuing response:

'But there is no life and death in the things we queue for but there is in livers.' (Sheila, age 70, Housewife, oldest, mainly male group)

Most comments emphasised the turn-taking aspect of the waiting list, but some comments framed the time spent as significant in a different way. The oldest group's response on this issue was linked to their strong commitment to prognosis as a criterion, and a view that time spent on the waiting list must imply that the patient's health is deteriorating over time, leading to a loss in life expectancy. Hence, far from being irrelevant, some members of the oldest group saw time on the waiting list as a negative factor:

'yes after 6 months you are going down hill aren't you. Your chances are going.' (Sandy, age 72, retired policeman, oldest, mainly male group)

An interesting comparison was made in the larger intermediate all-female group between prognosis, in terms of life years, and time spent on the waiting list:

'Well you are talking of 9 months as against 10 years ... the one guy he has waited 9 months more but the other guy could live 10 years more and I think 10 years outweighs 9 months.' (Maureen, age 55, clerical officer, larger intermediate all-female group)

This comment also shifted the focus from the turn-taking aspect of the waiting list to time waited as a cost in its own right, to be compared with the benefit of improved prognosis.

Whether the patient is being transplanted for the first time or is being re-transplanted

In all the focus groups despite the efforts of the facilitators in prompting the discussion, it was difficult to get the group members to discuss this criterion at length. Members tended to quickly move off this subject and consider the other

factors included in the exercise. The brief discussion around this criterion in all focus groups lent support to the view that it may not be ethical to re-transplant an individual when this would mean that another individual waiting for their first transplant would not receive a donor liver as a consequence:

'I don't know whether they should be given another chance or not. But if you do give somebody a second one is it depriving another person?' (Morag, age 59, housewife, larger intermediate all-female group)

'Well you could say that they have already had a go, let someone else have a turn and let them go through the stage of waiting on that waiting list until they get to the top.' (Tracy, age 30, confectioner, youngest, mixed group)

In the two intermediate all-female groups there was a strong tendency to assume that re-transplantation must compromise prognosis, so that candidates for re-transplantation were in effect tainted with failure:

'I'd rather get somebody right and back to normal than have another stab at somebody who might not be right.' (Kath, age 53, care assistant, smaller intermediate all-female group)

In these groups the re-transplantation issue also became bound up with fault, and with alcohol abuse:

'You're just abusing it aren't you ... using the privilege of ... being left on the waiting list. (Doreen, age 59, retired, smaller intermediate all-female group)

Social background of the individuals

Although there was a consensus of opinion that this extra information was important in all four focus groups, the presentation of further information regarding the social background of each of the individuals concerned (Appendix 2) made it more difficult for members to come to a decision regarding priority for transplantation:

'They have all got as far as I can see ... something that's worth having the liver transplant for, but they have all got something in their back-

ground that is making you stand back and think, “well no, not really”. So it’s made it even harder.’ (Emma, age 39, care assistant, youngest, mixed group)

In all four focus groups, ‘family responsibilities’ in the form of caring for dependant and young children were expressed as a valid criterion for prioritization:

‘Jane ... is the main carer for her grandchildren because her daughter is too mentally ill to look after them ... if anything happens to Jayne her grandchildren, who knows, will probably go into care. (Maureen, age 55, clerical officer, larger intermediate all-female group)

However, there was less agreement amongst group members as to the extent to which social standing should enter into the equation:

‘Is it fair to discriminate against (Adam) and say he doesn’t deserve a transplant because he is in and out of prison and is unlikely to get a stable job? That doesn’t seem to me to be a fair justification. (Jo, age 38, teacher, youngest, mixed group)

‘I would pick Tom ... when you read that Tom could possibly by receiving this operation go on to help other people in the wider issues. (Ruth, age 47, social worker, youngest, mixed group)

The most consistent thread through the groups discussion of work and family background is arguably a utilitarian concern for seeking to prioritize those patients whose survival was of most benefit to most people. This view was ultimately stronger than views about moral deservingness, as the latter was seen as expressing prejudice and emotion. The problem lay in the fact that all the patients offered different, but possibly comparable benefits, and the group members were not willing ultimately to agree that one kind of benefit was more important than another kind.

Discussion

The five criteria used in the study were seen as important in part because they can each be associated with one, or at the most two, of the

three main principles – equity, efficiency/utility and desert. In working with these criteria, it was expected that informants would reveal their thoughts around the associated principles. In the event, the relationship between the three principles and the five criteria was rather more complex than originally anticipated. This was most apparent in the case of age, time spent on the waiting list and responsibility for illness. Age can be approached as an opportunity to balance efficiency against equity and some informants responded accordingly. A minority in the three younger groups used the equity argument in favour of age as a criterion, while the oldest, mainly male group preferred the efficiency argument. However, there was also a linkage made in the larger intermediate all-female group between age and desert, with age being viewed as the accumulation of merit. In the case of time spent on the waiting list, equity was expected to be the justification for its use, on the basis of turn-taking. However, the oldest group took an efficiency-based approach to this criterion, and in the larger intermediate all-female group one comment suggested that time spent might be seen as accumulated merit through bearing the cost of delay, when compared with the benefit of improved life-expectancy. In the case of personal responsibility for illness, informants used desert-based arguments both for (position i) and against (positions iii and v) the use of this criterion. But an efficiency-based argument was also used in favour of using this criterion (position ii), and an equity-based argument was used against it (position iv).

The response to prognosis was rather different in that the efficiency principle remained the overall moral underpinning of this diagnosis. But informants extended their thinking into benefits other than absolute time gained. They also considered relative time, and quality of life during time gained, and in doing this they came up against the subjective nature of these benefits and the difficulties of making judgements on behalf of others.

Two of the criteria, age and time on the waiting list, generated another distinctive

response from some informants. The majority of informants seemed to prefer to view age in terms of broad life-stage zones which would distinguish clearly between the positions of children and 80-year olds but militated against discriminating between the 40-year olds and the 60-year olds, who were perceived as not sufficiently different. There was a tendency to see the significance of the wider age-difference as obvious and not needing justification – the term ‘natural’ was used more than once. Likewise the mechanistic, culturally sanctioned fairness of the waiting list was also attractive to two of the groups, and again the attraction was at least in part that its application was ‘easier’ than other criteria, that nobody had to make a judgement. Both these areas, wide age-differences and automatic turn-taking, might be seen as ‘default positions’ wherein informants sought obvious, ‘natural’ or externally sanctioned solutions, perhaps as a respite from the dilemmas presented by the rest of the discussion. It is interesting that both these ‘default positions’ seem to rest on the principle of equity. The turn-taking aspect of the waiting list clearly reflects this, and some comments suggested that the reasoning behind discrimination between 80-year olds and children would be based on the principle of equity rather than efficiency e.g. ‘they (the children) need a chance to grow’.

The reason/s as to why the first transplant vs. re-transplant criterion was not debated to the same degree as all of the other criteria are not entirely clear. However, it is likely that focus group members did not place as much importance upon this criterion as a discriminating factor. This observation draws parallels with the results of the quantitative survey from which this qualitative study originates.¹¹ That quantitative survey found that of the five criteria considered (these being identical to the five criteria used in this qualitative study), the majority of informants ranked first transplant over a re-transplant as the least important criterion overall.¹¹ What also appeared to happen in the present study was that groups found it difficult to keep this criterion in the frame of

their discussion without connecting it to other criteria.

Conclusions

The focus group members were more receptive to the importance of some criteria than others, although they saw some difficulties in applying all of the criteria presented. In a minority of cases they took up perspectives that seemed to involve an escape from difficult dilemmas into ‘obvious’ solutions, but for the most part they were willing to explore the possibilities of the criteria from a number of viewpoints, in a rather more varied way than might have been expected *a priori*. It is desirable that further research is conducted in this area, preferably based upon a wider range of the population in terms of class and culture than that represented here. Nonetheless these results suggest that members of the public are willing and able to engage thoughtfully and flexibly with the criteria. This provides some support, in terms of public response, for a more open and explicit system of donor liver prioritization than exists presently within the UK, based on wider criteria than time spent on the waiting list.

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References

- 1 Neuberger J. Allocating donor livers: should be given to patients most likely to benefit irrespective of the cause. *British Medical Journal*, 1997; **314**: 1140–1141.
- 2 United Kingdom Transplant Support Services Authority. *Audit of Liver Transplantation in the UK*. Bristol: UKTSSA, 1998.
- 3 Mullen P. Public involvement in health care priority setting: an overview of methods for eliciting values. *Health Expectations*, 1999; **2**: 222–234.

- 4 Bowling A. Health care rationing: the public's debate. *British Medical Journal*, 1996; **312**: 670–674.
- 5 Bowie C, Richardson A, Sykes W. Consulting the public about health service priorities. *British Medical Journal*, 1995; **311**: 1155–1158.
- 6 Moss H, Siegler M. Should alcoholics compete equally for liver transplantation? *Journal of the American Medical Association*, 1991; **265**: 1295–1298.
- 7 Ubel PA, Arnold RM, Caplan AL. Rationing failure: the ethical lessons of the retransplantation of scarce vital organs. *Journal of the American Medical Association*, 1993; **270**: 2469–2474.
- 8 Ubel P, Loewenstein G. The efficacy and equity of re-transplantation: an experimental survey of public attitudes. *Health Policy*, 1995; **34**: 145–151.
- 9 Ubel P, Loewenstein G. Distributing scarce livers: the moral reasoning of the general public. *Social Science and Medicine*, 1996; **42**: 1049–1055.
- 10 Neuberger J, Adams D, McMaster P, Maidment A, Speed M. Assessing priorities for allocation of donor liver grafts: survey of public and clinicians. *British Medical Journal*, 1998; **317**: 172–175.
- 11 Ratcliffe J. Public preferences for the allocation of donor liver grafts for transplantation. *Health Economics*, 2000; **9**: 137–148.
- 12 Charney MC, Lewis PA, Farrow SC. Choosing who shall not be treated in the NHS. *Social Science and Medicine*, 1989; **28**: 1331–1338.
- 13 Busschbach JJV, Hessing DJ, De Charro FT. The utility of health at different stages in life: a quantitative approach. *Social Science and Medicine*, 1993; **37**: 153–158.
- 14 Nord E, Street A, Richardson J, Kuhse H, Singer P. The significance of age and duration of effect in social evaluation of health care. *Health Care Analysis*, 1996; **4**: 103–111.
- 15 Health Economics Research Group. *Interim Data: Economic Evaluation of the Liver Transplantation Programme in England and Wales*. London: Brunel University, 2000.
- 16 Dolan P, Cookson R, Ferguson B. Effect of discussion and deliberation on the public's views of priority setting in health care: focus group study. *British Medical Journal*, 1999; **318**: 916–919.
- 17 Krueger R. *Focus Groups: a Practical Guide for Applied Research*. Thousand Oaks, CA: Sage, 1994.
- 18 Strauss A. *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press, 1993.
- 19 Crabtree B, Miller W. A template approach to text analysis: developing and using code books. In: Crabtree B (ed.) *Doing Qualitative Research*. Newbury Park, CA: Sage, 1992; 93–109.

Appendix 1: Descriptions of patient profiles

Jackie

Jackie is 40 years old.

She has spent 12 months on the waiting list for a liver transplant.

Jackie's need for a liver transplant has arisen because she has damaged her liver by drinking a lot of alcohol.

However, she has now given up alcohol, and has been assessed by a psychologist as unlikely to return to drinking.

This is Jackie's first transplant.

If the operation goes well, Jackie's expected length of survival following the transplant is 5 years.

Tom

Tom is 60 years old.

He has spent 3 months on the waiting list for a liver transplant. Tom's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease.

This is Tom's first transplant.

If the operation goes well, Tom's expected length of survival following the transplant is 15 years.

James

James is 40 years old.

He has spent 12 months on the waiting list for a liver transplant. James's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease.

This is not James' first transplant. He has been transplanted previously but the operation was not successful. This failure was due to clinical factors beyond his control.

If the operation goes well, James' expected length of survival following the transplant is 5 years.

Jane

Jane is 60 years old.

She has spent 12 months on the waiting list for a liver transplant.

Jane's need for a liver transplant has arisen because she has damaged her liver by drinking a lot of alcohol.

However, she has now given up alcohol, and has been assessed by a psychologist as unlikely to return to drinking.

This is Jane's first transplant.

If the operation goes well, Jane's expected length of survival following the transplant is 15 years.

Adam

Adam is 40 years old.

He has spent 3 months on the waiting list for a liver transplant. Adam's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease.

This is not Adam's first transplant. He has been transplanted previously but the operation was not successful. This failure was due to clinical factors beyond his control.

If the operation goes well, Adam's expected length of survival following the transplant is 15 years.

Appendix 2: Further information presented on social background

Jackie

Jackie is divorced and is now living in a long-term relationship. She and her partner have care of her two children from her marriage, aged 13 and 10.

Jackie worked for many years on the checkout at Sainsbury's. She is too ill to work at present

but if her health improves she is likely to be able to find similar employment without difficulty.

Tom

Tom is a widower with no children.

He is an eminent geneticist but he has had to retire from his full-time research post through ill health. However if his health improves he is certain to be offered consultancy in relation to a research project into genetic disease.

James

James has no children. He lives in a gay relationship with a long-term partner.

He is an electrician by trade but is too ill to work at present. If his health improves he would be able to earn a good living at his trade again.

Jane

Jane is married with a daughter in her 30s and two grandchildren. Jane is the main carer for her grandchildren, as her daughter is mentally ill and is often unable to look after her children.

Jane worked as a school teacher but retired in her 50s. She is too ill to work at present and has little prospect of paid work if her health improves.

Adam

Adam is married with three children aged 16, 13 and 10.

His employment history is irregular, unskilled and casual. He has also been involved in petty crime on a number of occasions and he has had two short prison sentences. He is too ill to work at present but if his health improves his prospects of regular and stable employment are not good.