Community preferences for the allocation of deceased donor organs for transplantation: a focus group study

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ABSTRACT

Background. Solid organ transplantation is the treatment of choice for those with organ failure, but suitable organs are a limited community resource. Little is known about community preferences for the allocation of those organs. We aimed to determine community preferences for organ allocation and reasons for their choices.

Methods. Participants were recruited from the community in four states in Australia. In focus groups, they identified and discussed attributes that they believed were important for allocating organs to potential recipients. Transcripts were analysed thematically.

Results. Thirteen focus groups with 114 participants were conducted. Four major themes emerged: (i) saving and improving the lives; (ii) lowering the risk of lost opportunities; (iii) fairness and (iv) accountability. While happy to discuss general principles, many were not comfortable making organ allocation decisions and were happy to defer to health professionals; this reticence tended to disappear when discussing the use of their own organs.

Conclusions. Participants wanted to save as many lives as possible as well as lower the risk of lost opportunities for those on the waiting list by maximizing the chances of success of every donation. A rational utilitarian ethical model of organ allocation, therefore, appeared to be the dominant framework adopted by the community. Key considerations were compatibility, high chance of peri-operative survival and favouring those with positive lifestyle and self-management choices. Communication between the transplant community and general community about organ allocation could be undertaken to create trust and shared understanding, which may ultimately increase organ donation rates in the future.

INTRODUCTION

Transplantation is the treatment of choice for those who have experienced organ failure but the demand for deceased donated organs substantially exceeds supply. The current median waiting time for a deceased donor kidney in Australia is between 4 and 6 years, but can exceed 10 years, depending
on the sensitization status, blood group and HLA compatibility [1]. In the USA, this waiting time is between 2 and 3 years depending on the blood type [2] and, in Europe, 12 people die every day waiting for a transplant [3]. There is now consistent data showing that a prolonged period on dialysis waiting for a transplant is associated with poorer outcomes [4, 5]. Waiting times have also been identified as a significant issue under conditions where an alternative treatment such as dialysis does not exist; recipients wait on average 200 days for a liver and 150 days for a heart [2], with an annual mortality rate for wait-listed patients of 10% [4]. With waiting lists as they are, the challenge clearly rests in not only increasing availability of donor organs, but also in deciding how these scarce organs should be allocated. As donor organs can be viewed as a community held resource, it is important to consult with the community to determine their views on how they think organs ought to be allocated.

In general, to receive a deceased organ donation, an individual must fulfill the criteria for placement on the waiting list. Criteria vary according to organ and setting but usually include age, severity of comorbidities, cancer and active infections, compliance, lifestyles and expected survival outcomes. Once on the waiting list, available organs are allocated using an algorithm based usually on urgency, matching, paediatric recipients and time on the waiting list. In some settings, candidates are only considered if they are judged to have a favourable life expectancy after transplant, for example, an 80 or 50% chance of 5-year survival for kidney and liver transplants, respectively [6]. This system can sometimes lead to disparities in the allocation of organs, with diabetics, older recipients (>65 years) and indigenous people being under-represented on the waiting list [1, 7–10].

We know that clinicians have often been conflicted themselves in making organ allocation decisions [11] and that general community members are open to a consultative process for organ allocation [12]. The aim of this study, therefore, is to better understand the views of the wider community regarding their preferences for how transplantable organs are allocated to recipients, in an effort to understand their perspectives on how this community-held resource should be allocated and determine if current allocation practices reflect community preferences.

**MATERIALS AND METHODS**

**Participants**

We conducted focus groups in four Australian states (New South Wales, Queensland, Victoria and South Australia). Community-based participants that were registered with a market research company were contacted by the market research company and invited to participate. Participants were eligible if they spoke and understood English, were aged 18–80 years and able to give informed consent. They were purposively sampled to enable each group to reflect a balance of numbers between male and female participants, a variety of cultural backgrounds and varying views on organ donation based on responses to the following question ‘on a scale of 1 to 10, how would you rate your attitude to organ donation with 1 being completely disagree and 10 being completely agree’?

Participants were grouped by age groups: 18–25 years, 26–49 years and >50 years to promote rapport and open discussion. Participants were offered reimbursement for their time and travel expenses. The University of Sydney, Human Research Ethics Committee approved this study.

**Data collection**

These focus groups form part of a wider study on community attitudes to organ donation [13]. All focus groups were facilitated by one of the authors (A.T. or M.J.I.). An observer (A.T. or K.H.) recorded field notes on group dynamics and interactions, participant characteristics, body language and the context surrounding the discussion. Preliminary questions about the participants’ thoughts and attitudes to deceased organ allocation were developed, based on a systematic review of the literature [14] and discussion among the research team. Second, a group discussion around factors that should influence decisions regarding allocation of organs was facilitated. The schedule is available on request. Participants were unlikely to be aware of the current allocation system in Australia, discussion was encouraged, but misnomers were not necessarily corrected. All sessions were recorded and transcribed verbatim. Focus groups were convened until we reached saturation, that is, when little or no new themes were emerging from subsequent groups.

**Data analysis**

Transcripts were analysed thematically to develop major themes associated with preferences for the allocation of deceased donor organs. Transcripts were entered into HyperRESEARCH (ResearchWare Inc., USA, Version 2.8.3). Transcripts were reviewed line-by-line by M.J.I. who searched for concepts, themes and ideas, and developed a preliminary coding scheme using an adapted grounded theory approach [15], incorporating negative case analysis [16]. Transcripts were also read by K.H., A.T. to discuss the preliminary coding. After discussion among the broader research team, M.J.I. refined the coding structure until it captured all relevant concepts. Reporting was done using the COREQ framework [17].

**RESULTS**

Thirteen nominal groups comprised of 7–10 participants (total n = 114), were conducted from May–August 2010 in Sydney (4), Melbourne (3), Brisbane (3) and Adelaide (3). Participant characteristics are provided in Table 1.

Forty-three (38%) participants reported that they were from other cultural backgrounds. Of the 110 participants whose ratings were reported, 20 (18%) participants rated their attitude to organ donation as ‘negative’ (from 1 to 4), 27 (25%) rated themselves as ‘neutral’ (5–6) and 63 (57%) rated themselves as generally positive (7–10).
Thematic synthesis

Respondents had little knowledge of current organ allocation protocols, but recognized that donor organs are a scarce resource and understood the need for consideration of multiple factors in the allocation of organs. However, they sometimes found it difficult to decide between equally important attributes. In considering these various attributes, when comparing 'hypothetical patients' (either defined by the facilitators or the respondents themselves), they often struggled to choose between two recipients they considered worthy, but different. However, individuals became much more sensitized to the principles surrounding allocation when the discussion focused away from broad general principles to the specifics of how they would like their own organs allocated; and the standards for the recipient were higher and respondents were more likely to focus on the importance of the personal factors of the recipients in greater detail. Participants wanted to know that their own donated organs would be treated with utmost care and only transplanted into what they considered the most worthy recipients with the potential for the best possible health outcomes.

Four major themes emerged from the thematic qualitative analysis of the focus group component of the study: (i) saving and improving lives; (ii) lowering the risk for lost opportunities; (iii) fairness and (iv) accountability (Figure 1).

Saving and improving lives. Participants wanted to save and improve the lives of as many people as possible. They felt that priority should be given to the most urgent and those who had the potential for the most improved quality of life and expected survival.

Medical urgency. Most respondents wanted to 'rescue' as many people as possible and agreed that medical urgency to receive an organ should be a high priority in the allocation of organs. In defining urgency, many believed that those who were 'about to die' or who were the 'sickest' should be of the highest priority. It was important to the respondents to 'save'

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\(^a\)Participant question: ‘On a scale of 1–10, how would you rate your attitude to organ donation with 1 being completely disagree and 10 being completely agree?’

FIGURE 1: Community perspectives about important factors for the allocation of deceased donor organs.

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Community preferences for the allocation of deceased donor organs for transplantation

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the greatest number of lives and not 'lose' anyone while they were waiting for an organ.

It’s not really a matter of how long you have been on the waiting list, it’s a matter of how serious your sickness is (Male, 25–50 years, Adelaide).

**Potential improvements in quality of life.** Many respondents understood the potential for improvements in the quality and quantity of life of organ recipients, and believed that those who received an organ would not only have another chance at life, but have the ability to lead a more productive and fulfilling life. They could empathize with those needing an organ and had a great desire to improve recipients’ quality of life. They, therefore, felt that those with the greater potential for a good quality of life should have priority.

It’s quality versus quantity. You might live for 10 years without the kidney on dialysis, but you might live five with a new kidney. It’s quality versus quantity. It’s a vast improvement on the quality that they’ve had (Female, 50+ years, Brisbane).

**Lowering the risk for lost opportunities.** While respondents wanted to save as many lives as possible, they also wanted to minimize lost opportunities caused by transplants that were not likely to have good outcomes. They wanted to ensure that, before an organ was offered to a recipient, they had the potential to survive the operation, were compatible with the organ, made positive lifestyle choices and practiced self-management, and did not have comorbidities that would significantly reduce their life expectancy. Each failed transplant was viewed not only as a loss for the recipient, but also as a lost opportunity for someone else on the transplant waiting list.

**Survival of the transplant procedure.** Participants felt that recipients should have a reasonable chance of surviving the transplant surgery. Losing a recipient at this stage of the transplant process meant a missed opportunity for others on the waiting list. Participants also made the distinction between short-term peri-operative survival and potential overall survival or life expectancy for the recipient. Although both were important, they felt longer-term survival could not be as accurately predicted and, therefore, should not be given a high weighting in the allocation decision.

Sometimes medical statistics go wrong though. Some people are told they have six weeks to live and five years later they are still alive (Female, 18–25 years, Brisbane).

**Compatibility of the donor and recipient.** Many participants felt that allocation of an organ should be made on compatibility of factors such as blood type and tissue matching as this would reduce the chance that the organ would be rejected. Rejection was viewed as a missed opportunity for another potential recipient. Some felt that the donor and recipient should also be matched on age; they thought that younger recipients should have access to younger organs as this would increase the potential longevity of the organ and potentially reduce the number of transplants needed over the long term.

It’s according to how much you match the actual organ donor. So the higher your rating then I think you should get it [the organ] first (Male, 18–25 years, Melbourne).

But what if the person that dies is 70? Do you want to put a 70 year olds heart in a nine-year-old child? (male, 18–25 years, Brisbane).

**Recipient’s current health and comorbidities.** Some participants felt the potential recipient should be in good enough health when receiving a donation so that they would not ‘die of something else’ as this was also viewed as a lost opportunity for someone else on the waiting list. The most commonly mentioned comorbidity that would deem the potential recipient to be ineligible for a transplant was active cancer.

You’ve got to be realistic, you’re not going to give a brand new set of lungs or kidneys to someone who’s got a brain tumour and he’s going to die (Male, 18–25 years, Sydney).

**Lifestyle factors (and compliance with medical regimens).** Most participants felt very strongly that some lifestyle factors should be a factor in the allocation of donor organs. These lifestyle factors included illicit drug use, alcohol abuse, smoking and previous non-compliance with medical regimens. Participants did not necessarily feel that potential recipients with these lifestyle habits did not deserve an organ. Many felt patients should be given a second chance, and that if they were given an organ, it may be the opportunity they needed to change their lifestyle. However, they also felt that if an organ was allocated to someone who had not demonstrated an ability to manage their graft, then someone else, who may ‘take better care’ of the organ and have a better outcome would miss out on the opportunity to receive a transplant. It was judged as not ‘fair’ for those with a healthy lifestyle to miss out.

You don’t want your organs to go to a druggie (male, 25–50 years, Adelaide).

It’s a history thing, like in the past how vigilant have they been with their health (Female, 18–25 years, Brisbane)?

**Fairness.** Most participants thought organs should be allocated fairly and equitably in respect to time served on the waiting list, age and the idea of reciprocity (whether a recipient was also prepared to be a donor themselves). They found it difficult, though, to make allocation decisions based on the recipient’s ‘community value’. The various criteria for fairness indicated in the focus groups are as follows:

**Time on waiting list.** Participants felt that priority should be given to those who had been on the waiting list for the longest, where other attributes such as urgency and need were equal, as this was considered ‘fair and equitable’.
The one that’s been on the waiting list the longest, provided that they’re both at the same health situation (male, 50+, years, Sydney).

**Age of recipient.** Many respondents thought that younger age should be a factor in priority for receiving an organ, particularly children; despite this, though, many had difficulty specifying an upper value for the age range that should have priority. Others believed that older recipients should have priority, as they could not afford to wait too long for an organ.

Like, after a certain age they should not be a priority. Younger people should be prioritized first … but it would be very hard to put an age limit on it though (female, 18–25 years, Adelaide).

**Community value.** Many participants found it difficult to judge priority for recipients based on their community value and the extent of family responsibilities. Factors mentioned for ‘community value’ included family responsibilities such as being the main breadwinner, or caring for aged parents or contribution to the community such as occupational role. Many felt, though, that it was very difficult to judge and a ‘dangerous path to go down’. The only factor that most participants generally agreed should be considered was a previous criminal conviction, but even that depended on the type of criminal conviction. The crimes that participants felt should always exclude an individual from receiving a transplant were murder, rape or pedophilia and other criminal convictions should be considered individually.

I think they’re important, but it’s hard to say well, this one’s got five children, this one’s just a single old lady, she doesn’t matter much. It’s really hard to make that decision but at the same time there are five children dependent on their mother (Female, 18–25 years, Brisbane).

You shouldn’t get it if you’re in jail (Male, 18–25 years, Sydney).

If you murder someone, you rape someone, in my opinion you shouldn’t be on the list (Female, 25–50 years, Adelaide).

**Reciprocity.** Some participants felt that those who were prepared to be a donor themselves and were registered as a donor, or their families were registered as donors, should have higher priority than those who were not prepared to be donors. Even if a person’s religion prevented them from donating, participants felt that they should have lower priority for receiving a donation.

If you’re not prepared to give them, you can’t take them … (Male, 18–25 years, Melbourne).

**Accountability.** Many participants expressed how difficult it would be to actually make real decisions about how donated organs were allocated. They appreciated the opportunity to provide input but were generally relieved that health-care professionals ultimately made the allocation decisions and they personally did not have to ‘choose’ between people to receive a transplant. Participants felt that almost everyone deserved an organ, but realized donated organs are a scarce resource and difficult decisions must be made. Where strong opinions were expressed, it was usually in regard to where they would like to see their own organs allocated.

I think that there are qualified people to make the right choices in this regard and although it’s very nice that I have an opinion and everything, it’s certainly not a qualified opinion, it’s very far from that (Male, 18–25 years, Melbourne).

I think let the professionals make it because they make it objectively (Female, 50+ years, Brisbane).

I wouldn’t like to think mine [donated organ] went to a murderer (Female, 50+ years, Melbourne).

**DISCUSSION**

In our study of community perspectives on the allocation of deceased organ donations, the participants wanted to save as many lives as possible and expressed a great deal of tension in choosing between worthy recipients. When faced with a choice, though, they felt that medically urgent patients facing imminent death should be given priority. Respondents also wanted to lower the risk for lost opportunities for those on the waiting list by maximizing each transplant opportunity. In general, participants had difficulty deciding which criteria should have higher priority in allocation. However, when they personalized the discussion by considering how their own organs should be allocated, they expressed preferences for specific criteria including: compatibility of donor and recipient, transplanting only those that have a high chance of peri-operative survival, recipients not at high risk of ‘dying of something else’ in the short term, treatment adherence (as a proxy for ability to care for graft in the future) and those that made lifestyle choices that they believed would not potentially increase the risk of graft failure (drug use, excessive alcohol intake, criminal activity and adherence to treatment regimens). Interestingly, participants valued a utilitarian perspective where organs should be allocated to maximize the number of lives saved; this was often tempered with consideration of factors such as time on the waiting list and urgency. They also expressed how difficult these decisions were to make and were ultimately relieved; there were health professionals to make the actual decisions about allocation.

These results are generally consistent with a recent systematic review of community preferences for the allocation of solid organs for transplantation where saving and improving lives, lowering the risk for lost opportunities, fairness and equity were important factors for the community in the allocation of organs [18]. However, in contrast, the participants in our
study did not believe that social or community ‘value’ should influence allocation decisions, the only exception was that certain criminal convictions would preclude eligibility for the transplant waiting list. This study also found for the first time that community members found it difficult to make decisions for allocation and believed that they would feel apprehensive if they had this responsibility. They found a great deal of difficulty in passing social judgement on others, a criminal conviction or being in jail was the only socially acceptable level of judgement that could still be drawn.

This is a high-quality and rigorously qualitative study of community preferences and attitudes towards deceased donor organ allocation. Qualitative methods are used for generating understanding about people’s attitudes, beliefs, values and perspectives; it captures the breadth of the data rather than the frequency of responses. We used software for the recording and auditable development of themes, and we used purposive sampling of participants. We endeavoured to include participants who, a priori, had varying views on organ donation and were from varying cultural backgrounds. While all of our participants spoke English, a proportion (38%) reported also speaking another language at home. This is comparable with the 39% of Australians who nominate their ancestry as being outside of Australia or England [19].

Currently, organ allocation protocols vary for different organs, but generally include criteria based on urgency, current comorbidities, weight, lifestyle, expected survival and time on the waiting list [6, 20, 21]. It was interesting to note that many of the current allocation criteria match the factors that our study participants suggested be used to allocate organs including medical urgency, compatibility, short-term survival and some comorbidities. However, participants seemed to place less emphasis on longer-term survival, as they felt that long-term survival, as embodied in the criteria of an 80% chance of surviving for 5 years following a kidney transplant [6], could not be accurately predicted by health professionals.

While the final decision on allocation may never fall directly to community members, community engagement on this topic is important. Programmes that aim to enhance confidence and capacity in consumer involvement in organ allocation policy should be encouraged to ensure first that the community has the potential to be involved in the discussion and second to ensure their views are articulated appropriately. This will arm health professionals with a range of criteria upon which to make allocation decisions. Further research should include studies that aim to understand why the community had difficulties in discussing allocation and choosing between recipients, and evaluation of community awareness campaigns that include relevant information on current organ allocation policies and the effect these campaigns have on community attitudes to organ donation and ultimately organ donation registration and organ donation rates. Framing community discussions around the allocation of their own organs may enhance the discussions and elicit more information about their real views on allocation.

The allocation of donated organs is wrought with moral and ethical complexities, coupled with considerable medical uncertainty. The allocation criteria for donated organs, both in Australia and internationally, are being debated with a view to improve efficiency and equity. Community views, particularly, with respect to equity and fairness criteria, should also inform these ongoing discussions. The allocation system for donor organs remains poorly understood by the community, and as such, there is room for continued effective communication and education programmes. While there may be an ethical consideration in better aligning current organ allocation policy with the preferences of the community, the finding, in this study, is that first, there appears to be at least some agreement between the factors the community considers important and those included in current allocation practices, and second, the community seemed to prefer that actual allocation decisions be deferred to higher medical authority. Perhaps, however, it is more on a pragmatic level that policy-makers should be seeking a better alignment between community preferences and policy as policies that are more in tune with the values of the community may encourage more individuals to make the decision to donate.

AUTHORS’ CONTRIBUTIONS
K.H., M.J.I. and A.T. were responsible for the conceptual design of the study. K.H., M.J.I. and A.T. carried out the focus groups and analysis; M.J.I. drafted the manuscript, all authors contributed to the revision of the article and approved the final version to be published. Ethical approval was granted from The University of Sydney, Human Research Ethics Committee.

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CONFLICT OF INTEREST STATEMENT
None declared.

REFERENCES

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