DISTRIBUTING SCARCE LIVERS: THE MORAL REASONING OF THE GENERAL PUBLIC

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Abstract—The transplant system has been criticized for not paying enough attention to efficiency in distributing scarce organs. But little research has been done to see how the general public views tradeoffs between efficiency and equity. We surveyed members of the general public to see how they would distribute organs among patients with varying chances of benefiting from them. In addition, we asked subjects to explain their decisions and to tell us about any other information they would have liked in order to make the decisions. We found that the public places a very high value on giving everyone a chance at receiving scarce resources, even if that means a significant decrease in the chance that available organs will save people’s lives. Our results raise important questions about whether the aims of outcomes research and cost-effective studies agree with the values of the general public.

Key words—transplantation, equity, prognosis, ethics, health policy

Both the medical community and the general public are becoming increasingly aware of the need to set limits on health care spending. Gone, it seems, are the days when every potentially beneficial service could be offered to every potential recipient. Instead, we have reached an era where we need to agree on what will be our health care priorities. Many hold the view that the primary goal of health care is to improve health. Thus, we ought to give priority to those medical services that are most effective in improving health. This view has led the U.S. government to increase its funding of outcomes research, with the goal of finding out how to spend scarce medical dollars most effectively [1]. And it has led medical journals to publish increasing numbers of cost-effectiveness studies, all of which are dependent on the assumption that the proper goal of health care is to maximize healthy lives [2, 3].

This push to increase the effectiveness of medical care has not spared the transplant system, which has been criticized for not distributing organs in ways that will maximize the effectiveness of transplant [4–9]. Faced with an unrelenting shortage of transplantable organs, the U.S. transplant community has developed a system to determine who will receive organs when they become available. This system gives some priority to the effectiveness of transplant, by giving priority to recipients whose antigens match those of the available donor. But it balances these efficiencies with other factors, including how sick patients are and how long they have been waiting for transplant [10, 11]. Taken to an extreme, some worry that this system will distribute organs only to those very ill patients who are least likely to benefit from them [8].

Despite the wide appeal of placing greater emphasis on outcomes in distributing scarce health care resources, evidence is accumulating that the public has a different view of how we ought to spend scarce health care dollars. For example, when Oregon attempted to ration health care according to cost-effectiveness, its rationing scheme was resoundingly rejected [12, 13]. Research suggests that this failure resulted, at least in part, because cost-effectiveness measures do not capture people’s values for setting health care priorities [14–18]. People are not only concerned with improving health care outcomes, but are also interested in distributing scarce resources fairly.

It is crucial to examine how important the public thinks outcomes should be in allocating scarce resources. Transplantation is an attractive platform for such an examination. First, transplantation offers an important medical service with an undeniable need to ration. Thus, scenarios involving transplant rationing are plausible to subjects who may not accept the need to ration in other settings. Second, the allocation decisions in transplant are dramatic, often deciding life and death. This forces people to think seriously about the importance of
using the resource carefully. Third, the success of transplant depends on public willingness to donate organs [19]. Thus, it may be important to make sure that allocation decisions are made in ways that do not violate public values.

In a previous study, we examined how the public views the tradeoff between equity and efficiency in distributing organs among primary transplant and retransplant candidates [20]. We found that people think retransplant candidates deserve less priority in receiving organs than primary candidates with similar prognoses. In addition, we found that while the public thinks prognosis is a relevant criterion to use in distributing scarce organs, few act as if it should be the only criterion. In the present study, we examine the importance of prognosis in determining how people would choose to distribute scarce transplantable organs. As part of this study, we presented subjects with a rationing decision in which they had to distribute 100 organs between two groups of patients who were categorized according to their chance of benefiting from transplant. We found that the larger the prognostic difference between patients, the less likely subjects were to give all patients an equal chance at receiving organs [21]. In this paper, we present the results of another aspect of this study, in which we asked subjects to explain their allocation choices and to list any other information they would have liked to have to make the allocation decision.

### METHODS

#### Subjects

We surveyed people assigned to jury duty at the Allegheny County Courthouse, in Pittsburgh, Pennsylvania. In this county, potential jurors are selected from voter registration records. The subjects were recruited by posting a sign in the juror waiting room announcing that those who filled out a survey would receive a candy bar.

#### Study design

Those volunteering to fill out a survey were randomly assigned to receive one of five survey versions. In all five versions (see the Appendix), subjects were asked how they would allocate 100 livers among 200 children who would otherwise die if not transplanted. The children were divided into two equal groups on the basis of a blood test that determined their likelihood of surviving if transplanted. We chose children as transplant candidates in order to reduce the number of other criteria that people might consider in making their decisions, such as social worth, ability to pay and personal responsibility for illness. The five versions were identical except in assigning prognoses to the two groups of patients. In one version, the blood test divided patients into a group of 100 children with an 80% chance of surviving if transplanted and a group of 100 children with a 70% chance of surviving. The other four versions included groups with the following per cent chance of surviving: 80/50, 80/20, 40/25, 40/10. In addition to asking subjects how they would allocate the organs, we also asked them to explain their allocation decisions in words and to list any other information they would have liked to have to make the allocation decision.

#### Data analysis

In this study we focus on subjects' answers to the open ended questions (numbers 2, 5 and 6 in the Appendix). These responses were coded independently by two research assistants. Discrepancies were resolved by one of the investigators (PAU). Although we asked respondents to explain their allocation decisions twice (questions 2 and 5 in the Appendix), these yielded largely redundant data; thus, the data from these two questions was combined.

### RESULTS

#### Demographics

169 Subjects volunteered to fill out a survey, with mean age of 44 and mean number of years of education of 15. Thirty five percent were male.

#### Allocation decisions

Subjects' allocation decisions are shown in Table 1. The most common allocation strategy was

<table>
<thead>
<tr>
<th>Percent of organs given to better prognostic group</th>
<th>80/70 (n = 32)</th>
<th>80/50 (n = 33)</th>
<th>80/20 (n = 34)</th>
<th>40/25 (n = 35)</th>
<th>40/10 (n = 35)</th>
<th>Total (n = 169)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 50</td>
<td>1 (3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (9)</td>
<td>1 (3)</td>
<td>5 (3)</td>
</tr>
<tr>
<td>50</td>
<td>17 (53)</td>
<td>11 (33)</td>
<td>9 (26)</td>
<td>14 (40)</td>
<td>5 (14)</td>
<td>56 (33)</td>
</tr>
<tr>
<td>51-75</td>
<td>7 (22)</td>
<td>9 (27)</td>
<td>7 (21)</td>
<td>5 (14)</td>
<td>10 (29)</td>
<td>38 (22)</td>
</tr>
<tr>
<td>76-99</td>
<td>3 (9)</td>
<td>2 (6)</td>
<td>10 (29)</td>
<td>4 (11)</td>
<td>13 (37)</td>
<td>32 (19)</td>
</tr>
<tr>
<td>100</td>
<td>4 (13)</td>
<td>11 (33)</td>
<td>8 (24)</td>
<td>9 (26)</td>
<td>6 (17)</td>
<td>38 (22)</td>
</tr>
</tbody>
</table>

In all cases, the group 1 patients were those with the better prognoses.
Distributing scarce livers

Table 2. Subjects' reasons for making allocation decisions

<table>
<thead>
<tr>
<th>Response category</th>
<th>Explanation</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve survival</td>
<td>Wanted either to maximize or improve survival beyond that of a random distribution of organs</td>
<td>&quot;It maximizes the number of lives saved.&quot;</td>
</tr>
<tr>
<td>Deserve a chance</td>
<td>Thought that all deserve some chance or all deserve an equal chance</td>
<td>&quot;It saves more lives.&quot;</td>
</tr>
<tr>
<td>Prognosis unpredictable</td>
<td>Felt that blood test was bad, that all such tests are bad, or that group predictions are not useful for individual decision making</td>
<td>&quot;I do not believe a test should or could correctly predict the outcome of such a delicate procedure.&quot;</td>
</tr>
<tr>
<td>Good prognosis</td>
<td>Thought that group 2 patients had too good a prognosis to ignore, or that prognostic difference between groups was too small to determine allocation</td>
<td>&quot;A 10% difference in survival does not seem significant enough.&quot;</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>&quot;Because the % is close, 80/70, an equal chance should be given to each group.&quot;</td>
</tr>
</tbody>
</table>

Reasons for allocation decisions

The reasons people gave for their allocation choices fell into the five broad categories listed in Table 2. Ninety six subjects’ reasons were categorized as ‘improve survival.’ This category included responses such as “it maximizes the no. of lives saved,” and “because group 1 [the better prognostic group] is more likely to survive.”

Eighty one subjects’ reasons were categorized as ‘deserve a chance.’ This category included responses such as “everyone deserves a chance,” “everyone deserves an equal chance,” and “needy people deserve transplants, whatever their chance of survival.” It also included comments such as “If I or my child were a member of either group, I would want a fair chance of receiving a transplant.” And it included responses in which subjects stated that organs should be given on a first-come-first-serve basis, because this strategy essentially gives all candidates a chance at transplant.

Twenty four subjects’ reasons were categorized as ‘prognosis unpredictable.’ This category included responses such as “Because the survival chances are only based on one blood test,” and “Special circumstances in 50% group could enhance candidates chance of survival.”

This justification was distinguished from another, ‘good prognosis,’ in which 10 respondents stated that they believed the prognostic information, but did not think that it warranted giving all the organs to the better prognostic group. This category included responses such as “A 10% difference in survival does not seem significant enough to prompt more availability to transplants,” and “I could justify giving the livers to children who had a 100% chance of survival and denying livers to children who had a 0% chance of survival. Any other ratio (90% vs 10%, 80% vs 20%, 70% vs 30%, etc.) becomes increasingly difficult.”

Fourteen subjects’ reasons were categorized as ‘other.’ This category included 6 subjects who stated that they gave a small number of organs to the worse prognostic group because they wanted to allow research to be done in order to improve the chance that people like them will have a better chance of surviving in the future. It also included one subject who stated that “I believe in God. God doesn’t work in numbers,” and another who wrote “Do not put any children through all the trauma and pain of surgery just on the pretense he/she may have a slight chance to survive!!!!” Interestingly, this last subject gave twenty percent of the organs to a group of candidates with a 10% chance of sur-

Table 3. Subjects’ reasons for making allocation decisions: distribution of responses by allocation choice

<table>
<thead>
<tr>
<th>Allocation choice</th>
<th>≤50% of organs to the better prognostic group</th>
<th>51–99% of organs to the better prognostic group</th>
<th>100% of organs to the better prognostic group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase survival</td>
<td>2</td>
<td>58</td>
<td>36</td>
<td>96</td>
</tr>
<tr>
<td>Deserve a chance</td>
<td>44</td>
<td>37</td>
<td>0</td>
<td>81</td>
</tr>
<tr>
<td>Prognosis unpredictable</td>
<td>16</td>
<td>8</td>
<td>0</td>
<td>24</td>
</tr>
<tr>
<td>Good prognosis</td>
<td>8</td>
<td>2</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>6</td>
<td>1</td>
<td>14</td>
</tr>
</tbody>
</table>

* Data reflect both responders with multiple answers and nonresponders.
survival, suggesting that by ‘slight chance’ she meant something less than even 10%.

Table 3 reports the distribution of these reasons according to subjects’ allocation choices. Of the subjects who gave 100% of the organs to the better prognostic group, almost all justified their decision based on maximization of survival. Of the subjects who gave 50% or less of the organs to the better prognostic group, the majority justified their decisions on the grounds that everyone deserved a chance at transplant. A smaller number used other reasons. Some divided the organs equally because they did not believe the prognostic test, such as one subject who stated “I don’t believe blood testing are the only factors for rejection of transplanted organs.” Of the subjects who gave from 51 to 99% of the organs to the better prognostic group, many used a combination of reasons to explain their choice. For example, one respondent in the 40/10 survey version gave 90% of the organs to the better prognostic group, stating “I would like to save as many lives as possible and still give hope to the group that has the least chance to survive.” A respondent in the 80/70 survey version gave 60% of the organs to the better prognostic group, stating “If the children in group 1 [the better prognostic group] have a greater chance of survival, then the greater percentage of livers should be given to them. However, the children in group 2 [the worse prognostic group] should not be denied the chance for survival altogether just because that chance is more slim.” These people, in effect, were trying to strike a balance between equity and efficiency.

Other information desired

When asked what other information they would want to have before making this allocation decision, subjects presented a wide range of desires. Seventy six stated that they wanted to know if there were any other prognostic variables that would help improve our ability to predict successful transplants, such as information about other illnesses that patients have or about how well the patients match the prospective donors. Thirty three wanted to give priority to those who were in more urgent need of transplant and nineteen wanted to give priority to those who have been waiting longest for transplant. Other desired information is shown in Table 4.

**DISCUSSION**

Our study shows that prognosis is an important factor in how subjects chose to distribute transplantable livers among children needing transplant. However, as important as prognosis was in determining their allocation decisions, the majority of subjects felt that prognosis alone should not determine allocation. This held true even for those subjects asked to distribute organs between a group of patients with an 80% chance of benefiting and a group with a 20% chance.

The major factor limiting subjects’ use of prognosis to distribute organs was fairness. Many subjects felt that everyone with some chance of benefiting from transplant deserves some chance at receiving available organs. This view has important implications for medical outcomes research and health care policy. Many outcomes studies and cost-effectiveness analyses assume that health care priorities ought to be set in a way to maximize health. In the scenario we provided subjects, this assumption would lead to a policy that gave organs to those more likely to benefit from them. That is, if we have accurate ways to predict transplant outcomes, we ought to use them to decide who to transplant. Our research shows that many members of the public do not agree with this assumption. Instead, the public places a high value on equity in distributing scarce resources, even if this means poorer outcomes.

Subjects’ allocation decisions were also influenced by whether or not they had confidence in the predictive abilities of the prognostic blood test. Some subjects who distributed organs equally between the two prognostic groups stated that they did not believe in the accuracy of the test. This lack of confidence had several causes. For some subjects, it merely reflected another way of saying that organs ought to be distributed fairly between groups. For these subjects, no prognostic evidence could be powerful enough to determine allocation. For other subjects, this lack of confidence reflected a more sophisticated view of predictability, in which subjects felt that other prognostic information could help divide the patients up more accurately. This was reflected in the number of subjects who requested more prognostic information and in comments such as one subject who distributed organs equally stating that “Special circumstances in 50% group could enhance candidates chance of survival.”

Table 4. Other information desired by subjects

<table>
<thead>
<tr>
<th>Information desired</th>
<th>Number of subjects*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional prognostic variables</td>
<td>76</td>
</tr>
<tr>
<td>Urgency of illness</td>
<td>33</td>
</tr>
<tr>
<td>Length of illness/waiting time</td>
<td>19</td>
</tr>
<tr>
<td>Patient’s age</td>
<td>17</td>
</tr>
<tr>
<td>Level of family support</td>
<td>16</td>
</tr>
<tr>
<td>Predicted quality of life after transplant</td>
<td>9</td>
</tr>
<tr>
<td>Ability of family to donate organ</td>
<td>8</td>
</tr>
<tr>
<td>Family history or genetic predisposition</td>
<td>7</td>
</tr>
<tr>
<td>Ability to pay for transplant</td>
<td>5</td>
</tr>
<tr>
<td>History of previous transplant</td>
<td>4</td>
</tr>
<tr>
<td>Religion of child and/or family</td>
<td>2</td>
</tr>
<tr>
<td>Citizenship—U.S. vs other</td>
<td>2</td>
</tr>
<tr>
<td>Race of child</td>
<td>2</td>
</tr>
<tr>
<td>Size of family</td>
<td>2</td>
</tr>
<tr>
<td>Criminal history</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
</tbody>
</table>

*Subjects could list as many responses as they wished.*
Subjects' allocation decisions were also influenced by how well they understood how to use the prognostic information to maximize survival. As we report elsewhere, a majority of subjects did not understand that survival would be maximized by giving all the organs to the better prognostic group [20]. This lack of understanding limited the likelihood that subjects would give all the organs to the better prognostic group. Subjects' explanations of their allocation decisions provide some insight into why they may not have understood. A number of subjects receiving the 80/20 and 40/10 survey versions gave 80% of the organs to the better prognostic group. As one subject stated, this allocation allowed organs to be “distributed equal to survivability.” This reasoning is consistent with the results of psychology experiments in which subjects were asked to use probabilistic information to predict the result of rolling a colored die with four green and two red sides [22]. A common strategy involved guessing green two out of three times, matching the probability of the colorings, even though the optimal strategy should be to guess green every time. In effect, some of our subjects thought that there was some way to give the organs to those patients within each group who would survive, a capability not given to us by the prognostic information.

What implications do these findings have for outcomes research and transplant policy? A fundamental tenet of much outcome research is that the primary goal of how we spend health care dollars is to maximize measurable outcomes. For example, cost-effectiveness analysis, a common technique used in outcomes research, rests on the assumption that the overall goal of health care policy ought to be to get the most amount of benefit per dollar spent [3, 23, 24]. This study adds to accumulating evidence that cost-effectiveness analysis may not reflect many people's values [12]. For years, economists and philosophers have pointed out the inconsistencies in how much people are willing to spend to save statistical lives vs identifiable lives [25, 26]. The only attempt in the United States to set health care policy according to cost-effectiveness failed [12]. More recently, a number of empirical studies have shown that the way that values are incorporated into cost-effectiveness analyses, through ‘utilities’, do not accurately reflect people's social priorities [17, 18, 27]. Other studies have shown several other important differences between people's values and the values inherent in cost-effectiveness analysis. First, when faced with treatment decisions involving patients with different illnesses, people prefer treating the more severely ill patients, even if that does not bring as much benefit as treating those less severely ill [14]. Second, when faced with treatment decisions between people who are equally ill, but for whom some will improve more with treatment than others, people are reluctant to favor one group of patients over another [15].

Our study looks at another question. We asked people to choose between treating groups of patients who have the same illness and who stand to improve, after treatment, to the same level of function but who have a different chance of being improved to that end state. We know of only one other study that looked at this factor and here the chance of benefiting was only varied over two points [28]. Our study, then, looks at this issue from a new angle and confirms the findings of earlier studies, namely that many people in the general public are interested in goals other than merely maximizing measurable health outcomes.

This does not mean that outcomes should not be measured, nor should this be taken as evidence that outcomes research should not play a role in health care policy. Instead, it should serve to caution us about what we do with the information we gain from outcomes research, especially that information which we use to compare the relative benefits of curing one type of condition vs another.

We must be cautious about generalizing the findings of our research. Our subjects were prospective jurors in the United States. The attitudes of people in other countries may be different than those of our subjects. In addition, although jurors are a fairly representative sample of the U.S. population, they are not a perfectly representative sample by any means. They are taken from voter registration records, and that already skews the sample toward a particular type of person. In addition, filling out a survey in the space of a courthouse may affect people's thinking. We happen to think this probably affects their thinking in a good way. They are busy fulfilling a public duty and this may be a nice setting in which to ask them to give their ideas of important public policy decisions. However, it remains to be seen whether people answering a similar survey in a different setting would respond differently.

In addition, we should be cautious about using the results of this study as evidence that transplant policies should de-emphasize efficiency in order to increase equity. First, some of the views expressed by our subjects do not deserve a place in any kind of policy, such as a subject who stated: “Biracial people should not receive transplants.” Second, our scenarios may have been too thin to accurately assess people's values. Survey research is often prone to such problems, with slight changes in wording leading to important shifts in responses [29]. To the extent that our survey does not reflect people’s actual values, we need to be cautious about incorporating them into policy. Third, it does not make sense to base policies on the views of people who do not understand the issues involved. Complicated matters such as how and when to use outcomes data to determine allocation may simply exceed what many people in the public can comprehend. While attempts should be made to educate the public about these matters, ultimately those
who understand them (including members of the general public) should be the ones to decide how to use them.

While the public's ability to make acceptable rationing decisions may be limited, public opinion regarding these matters should not be dismissed. Indeed, much of the value of democracy rests on an assumption that the public is capable of making important and difficult decisions. As long as we function in any type of democratic state, we ought to test how members of the general public view important social issues. And we ought to learn how different presentations of the 'facts' will affect people's attitudes. While experts deserve an important role in setting transplant allocation priorities, these decisions involve important social values, and thus the public also deserves some role in making them.

The validity of basing transplant policies, at least in part, on public values is supported by the similarities between present allocation policies and the results of this study. The present policy does not rely exclusively on efficiency to allocate organs, but tempers this with concern for equity. In fact, a number of subjects asked for information on waiting times and level of family support, factors that are already accounted for in the present system. What is not clear, however, is whether the public places greater value on equity than does the transplant community. It is possible that many transplant surgeons would not transplant a patient whose chance of surviving after transplant was only 20%. Yet a majority of subjects in this study would give them almost equal priority in receiving organs as patients with much better prognoses. Further research is needed to be able to compare the views of the public with those of the transplant community.

CONCLUSION

The high value that study subjects placed on equity raises questions about the appropriateness of using cost-effectiveness and other outcome measures as the sole means of determining health care priorities. Transplant policies that base allocation purely on maximizing the efficiency of transplant will violate the values of many members of the public. The present allocation system, which attempts to strike a balance between efficiency and equity, is a better reflection of most people's values. As we move to incorporate more prognostic predictors into transplant allocation schemes, we need to be aware of how the public will perceive the system's equity. It is beginning to look like many members of the public will not agree with a system based completely on efficiency.

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REFERENCES

11. UNOS. Articles of Incorporation. 27 June 1995.
Distributing scarce livers


**APPENDIX**

We are going to ask you about a health issue. There are no 'right' or 'wrong' answers to these questions. As you may know, there is a shortage of livers available for those who need transplants. This problem is especially bad for children. Suppose that 200 children are waiting to receive a liver transplant, none of whom have any other health problems. They need to receive these transplants within one year or they will die. In that time, only 100 usable livers will become available. Children who do not receive a transplant will die.

A blood test is available that divides the children into two groups, each with a different chance of surviving transplant. No other information predicts their outcome as reliably as this blood test.

Group 1 (100 patients): 80% chance of surviving if transplanted

Group 2 (100 patients): 50% chance of surviving if transplanted

(1) What percentage of the 100 livers do you think should go to each group?

Group 1: __ %
Group 2: __ %
Total: 100 %

(2) Please explain why you recommend this particular distribution of organs.

(3) What distribution of organs to children in groups 1 and 2 do you think would save the largest number of lives?

Group 1: __ %
Group 2: __ %
Total: 100 %

(4) Why do you think this distribution would save the largest number of lives?

(5) If your answer to (1) is different than (3), please explain why you did not choose to save the largest number of lives.

(6) What other information about the children would help you to decide how to distribute the organs?