Public Perceptions of the Importance of Prognosis in Allocating Transplantable Livers to Children

PETER A. UBEL, MD, GEORGE LOEWENSTEIN, PhD

Background. The system to allocate scarce transplantable livers has been criticized for not giving enough weight to the prognoses of the patients receiving the transplants, but little research has been done looking at how the public weights the relative importances of efficacy and equity in distributing the organs. Methods. This study was an experimental survey of prospective jurors asked to distribute transplantable livers among transplant candidates grouped according to their prognoses. The relative prognoses of the transplant candidates were varied across survey versions. Results. As the prognostic difference between transplant groups increased, the subjects became less likely to distribute the organs equally between them (p < 0.005). However, the subjects’ willingness to base allocation on prognosis was moderated by a number of factors, including their understanding of how to use prognostic information and their attitudes toward using prognostic information for individuals versus groups. Thus, even when the relative prognoses of transplant groups differed by 60%, less than a fourth of the subjects were willing to give all the organs to the better-prognosis group. Conclusion. Many subjects feel that prognosis is an important consideration in allocating scarce livers. However, few are willing to base allocation purely on maximizing survival. Policies that base allocations purely on outcomes will violate the values of a significant portion of the public. Key words: transplantation; equity; prognosis; ethics; health policy. (Med Decis Making 1996;16:234-241)
ues people place on equity and efficiency in distributing organs.

In a previous study, we examined how the public views the tradeoff between equity and efficiency in distributing livers among primary transplant and retransplant candidates. We asked subjects to allocate one hundred livers among two hundred adults who needed transplants. The subjects were given one of two surveys. In the "blood test survey," the potential transplant patients were broken into two groups based on the results of a blood test that predicted their chances of surviving transplant. In the "retransplant survey," this prognostic difference (which was the same size as in the "blood test survey") was explained by the fact that the worse-prognosis group consisted of retransplant candidates, while the better-prognosis group members were patients waiting for their first transplants. We found that the subjects receiving the retransplant survey were less likely to give organs to the worse-prognosis group than were the subjects who received the blood test survey. In effect, the subjects felt that retransplant candidates deserved less priority in receiving organs than did primary candidates with similar prognoses.

Although that study was designed to find out whether subjects treated primary transplant candidates differently than retransplant candidates, another finding became apparent to us: the subjects did not place as high a priority on prognosis as we had predicted they would. One third of the subjects distributed the available organs equally between the prognosis groups, suggesting that they did not think prognosis was a relevant allocation factor. In fact, only 18% of the subjects felt that prognosis alone should determine who received available organs. This reluctance to base allocation only on prognosis, which implies a sacrificing of lives, deserves greater attention. Were the subjects simply unaware of how they could use prognostic information to maximize transplant survival? Or were they reluctant to base allocation on prognosis because they felt that other moral factors deserved attention, such as patients’ ages or levels of responsibility for their illness? Or were the subjects simply unwilling to abandon entire groups of identifiable patients, feeling it would be better to give them some organs rather than select a whole group of people who would be doomed to die?

In the present study, we examined in greater depth the importance of prognosis in determining how people choose to distribute scarce transplantable organs. Specifically, we examined how a variety of prognostic differences between groups of children needing transplants affected public perceptions of their suitability for liver transplantation. In addition, we tested whether people understood, at the simplest level, the effect that their decisions would have on aggregate survival. Finally, we test to see whether the framing of allocation problems as involving distinct groups of potential recipients versus as individual patients affected people’s allocation preferences.

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 study 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 they did not receive transplants. The children were divided into two equal groups on the basis of a blood test that established their likelihoods of surviving if they received transplants. We chose children as the transplant candidates in order to reduce the number of other criteria that people might consider in making their decisions, such as age, social worth, ability to pay, and personal responsibility for illness. The five survey versions were identical except in the prognoses assigned 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 with transplants and a group of 100 children with a 70% chance of surviving. The other four versions included groups with the following percentage chances of surviving: 80/50, 80/20, 40/25, 40/10. To see whether subjects understood the implications of their allocation decisions, we asked them to indicate what distribution of organs they thought would maximize the number of lives saved by transplantation. Finally, we asked them to specify whether, if the 200 patients were individually ranked according to prognosis instead of categorized by group, they would like to make use of the ranking information in assigning organs.

DATA ANALYSIS

Continuous variables, such as percentage of organs distributed to the better-prognosis group
Table 1  Characteristics of Respondents to the Transplant-allocation Survey

<table>
<thead>
<tr>
<th>Survey Version, % Chance of Recipient Survival</th>
<th>Male</th>
<th>Age (mean)</th>
<th>Extent of education (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>80/70% (n = 31)</td>
<td>32.3%</td>
<td>45.1 years</td>
<td>15.4 years</td>
</tr>
<tr>
<td>80/50% (n = 33)</td>
<td>33.3%</td>
<td>41.9 years</td>
<td>15.0 years</td>
</tr>
<tr>
<td>80/20% (n = 32)</td>
<td>31.2%</td>
<td>42.4 years</td>
<td>14.7 years</td>
</tr>
<tr>
<td>40/25% (n = 35)</td>
<td>37.1%</td>
<td>46.4 years</td>
<td>14.7 years</td>
</tr>
<tr>
<td>40/10% (n = 35)</td>
<td>40.0%</td>
<td>44.5 years</td>
<td>15.0 years</td>
</tr>
<tr>
<td>All Respondents (n = 166)*</td>
<td>34.9%</td>
<td>44.1 years</td>
<td>14.9 years</td>
</tr>
</tbody>
</table>

*Three respondents did not provide demographic data.

Table 2  Allocation Decisions of the 169 Respondents: Liver Transplants Allocated to the Better Prognostic Groups

<table>
<thead>
<tr>
<th>Organs Allocated to Better Prognostic Group, % of Available Organs</th>
<th>Percentage of Respondents Making Choice by Survey Version*</th>
<th>Percentage of All Respondents Making Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>80/70% (n = 32)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>80/50% (n = 33)</td>
<td>53</td>
<td>33</td>
</tr>
<tr>
<td>80/20% (n = 34)</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>40/25% (n = 35)</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>40/10% (n = 35)</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>&lt;50% allocated</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>50% allocated</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>51-75% allocated</td>
<td>26</td>
<td>40</td>
</tr>
<tr>
<td>76-99% allocated</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>100% allocated</td>
<td>24</td>
<td>26</td>
</tr>
</tbody>
</table>

*Survey versions are percentage chances of recipient survival.

(BPG), were compared across survey versions using ANOVA. The effects of the difference [% surviving in BPG – % surviving in worse-prognosis group (WPG)] and the ratio [1/(BPG + % WPG)] on allocation decisions were analyzed by performing a regression analysis with differences between and ratios of the two prognosis groups as the independent variables and allocation choice as the dependent variables. Dichotomous variables were analyzed by Pearson’s χ². Although the subjects generally completed the forms carefully, some responses were left blank or were uncodeable for other reasons (e.g., illegibility). The missing data are responsible for discrepancies in degrees of freedom between the different analyses.

Results

DEMOGRAPHICS

One hundred and sixty-nine (169) subjects volunteered to fill out a survey. Their demographic data are shown in Table 1. There were no statistically significant differences in age, gender, or education among the respondents completing the five survey versions.

ALLOCATION CHOICES

Table 2 shows the percentages of the available organs that subjects allocated to the better-prognosis group. The mean allocations of organs to the better-prognosis group were significantly different across survey versions [F(4,162) = 2.6, p = 0.04131, ranging from 62.7% in the 80/70% version to 75.4% in the 40/10% version. The subjects chose a wide range of allocation strategies. The most common allocation strategy was to distribute the available organs equally between the two groups of patients, with 56 of the 169 subjects (33%) choosing this strategy. The next most common strategy was to give all the organs to the better-prognosis group, a choice made by 38 subjects (22%). All but five of the remaining subjects gave 51% to 99% of the organs to the better-prognosis group.

The significant differences in mean allocations across survey versions resulted in large part from the number of subjects in each version who chose to allocate 50% of the organs to each group of patients. When we compared the numbers giving 50% of the organs to the better-prognosis group across survey versions, the between-group differences were highly significant [χ²(4) = 14.9, p < 0.0051]. In general, the subjects were more likely to give the two groups of patients equal numbers of livers when the prognostic difference between the groups was small. In the version with the smallest prognostic difference between patients (80/70%), 53% of the subjects allocated equal numbers of livers to the two groups. In contrast, in the version with the largest prognostic difference (80/20%), only 26% allocated equal numbers of livers to the two groups.

Although our design varied both absolute and relative differences between prognoses across survey versions, we did not include enough versions to examine their independent effects. The numbers of livers allocated to the better-prognosis groups were significantly related to differences between [t(165) = 2.6, p < 0.011 and ratios of t(165) = 2.4, p C 0.021]
the better- and worse-prognosis groups when the effect of each variable was evaluated independently using regression. However, when we introduced both variables into the regression equation, due to collinearity, both variables became insignificant. A virtually identical pattern was observed substituting the percentage of subjects allocating equal numbers of livers to the two groups as the dependent variable. With our data, therefore, we are unable to determine to what degree people care about absolute as compared with relative differences in prognosis.

SUBJECTS’ UNDERSTANDING OF THEIR ALLOCATION CHOICES

A majority of the subjects (57.4%) did not know how to distribute the organs in a way that would maximize overall survival; only 72 subjects (42.6%) correctly responded that survival would be maximized by giving 100% of the organs to the better-prognosis group. Understanding of how to maximize survival did not differ across survey versions, nor was it affected by either the absolute or the relative prognostic differences. Subjects’ understanding of how to maximize survival was not influenced by age \(F(1,161) = 0.34, p > 0.51\) but it was significantly related to level of education \(F(1,161) = 2.9, p < 0.0051\) and gender \(F(1,161) = 4.2; p < 0.00011\), with more educated subjects and men more likely to respond that giving 100% of the organs to the better-prognosis group would maximize survival. We conducted a regression analysis to determine the interrelationship between allocation decisions, perception of what distribution maximizes survival, and gender. This showed that maximization perceptions were influenced by gender \(t(162) = 2.3, p < 0.031\) and allocation decisions were influenced by maximization perceptions \(t(158) = 11.7, p < 0.00011\), but gender did not influence allocation decisions after controlling for maximization perceptions \(t(154) = 11.3, p > 0.41\). This pattern of results indicates that gender influences allocation decisions only indirectly, via its influence on maximization perceptions.

The allocation decisions of the subjects who did not understand how to maximize survival were markedly different from the decisions of those who did understand (Table 3). Those who did not understand were more likely to distribute the organs equally among the two groups than were those who did understand, with 48% choosing an egalitarian distribution compared with 14%. Of those who did not understand, only 3% gave all the organs to the better-prognosis group, whereas of those who did understand, almost half (49%) did so. It should be noted, however, that some of those who did not understand how to maximize survival may have distributed less than 100% of the organs to the better-prognosis group thinking that this distribution would maximize survival. When we compared these subjects’ allocation choices with their incorrect interpretations of how to maximize survival, we found that 53 (55%) distributed organs in ways that they thought would maximize survival. This number is close to the 49% of those who understood how to maximize survival who gave all the organs to the better-prognosis group.

CHOOSING TO USE OR IGNORE INFORMATION

For groups of patients. After the subjects had been asked to distribute the available organs between the two prognostic groups, they were asked whether, if given a choice, they would prefer to ignore the blood test and randomly distribute the organs to the children. Seventy subjects (41%) said they would rather ignore the information. This may be compared with the 56 subjects (33%) who chose to distribute the organs equally between the two groups in the original question. Since ignoring the information leads to essentially the same distribution of organs as distributing them equally between the two groups, framing the issue as a choice to use or ignore information led to a more egalitarian response than did the original framing of the question.

For individually ranked patients. When the subjects were told that there was information available that could rank the individuals according to their prognoses, only 39 subjects (23%) chose to ignore the prognostic information.

Discussion

Our study showed that prognosis was an important factor in how subjects chose to distribute transplantable livers among children needing transplants. The greater the prognostic difference between the two groups of transplant candidates, the less likely the subjects were to ignore prognosis in distributing available livers. However, as important as prognosis

<table>
<thead>
<tr>
<th>Organs Allocated to Better Prognostic Group, % of Available Organs</th>
<th>Percentage of Respondents Making Choice*</th>
</tr>
</thead>
<tbody>
<tr>
<td>In = 71</td>
<td>In = 96</td>
</tr>
<tr>
<td>50% allocated</td>
<td>14</td>
</tr>
<tr>
<td>51-75% allocated</td>
<td>16</td>
</tr>
<tr>
<td>76-99% allocated</td>
<td>18</td>
</tr>
<tr>
<td>100% allocated</td>
<td>49</td>
</tr>
</tbody>
</table>

*Two subjects did not answer the maximization question.
was in determining their allocation decisions, few made their allocation decisions purely on the basis of prognosis. Even when distributing organs between patients with an 80% versus 20% chance of survival, only 24% of subjects gave all the organs to the better-prognosis group.

Several studies provide important context for the study reported here. A number of studies have shown that many people think issues of fairness are more important than simply maximizing measurable health outcomes. Other studies have shown that, when asked to choose among patients with different illnesses, people prefer treating severely ill patients over those less ill, a preference that cannot be explained by any increase in “utility” that is gained by treating the severely ill patients. Two other studies have shown that, when asked to choose among patients with the same illness, people distribute scarce resources in ways that will equalize outcomes of the two groups, even if more overall benefit could have been gained by favoring one group over the others. For example, subjects were asked to allocate 48 pain pills between two patients suffering from a chronic painful condition. One patient was said to need one pill per hour of pain relief and the other patient was said to need three pills per hour of pain relief. The most common strategy for the subjects was to divvy up the pain pills between the patients in ways that equalized the numbers of hours of pain they felt, even though more hours of pain relief could have been attained by giving more pain pills to the first patient.

These studies show that at least under certain circumstances, people do not act in ways consistent with utilitarianism. Utilitarianism is a theory of justice that holds that the best allocation of scarce resources is that allocation which will maximize overall utility.” Utilitarianism stands in contrast to other theories of justice that place more emphasis on helping needier people whether or not this maximizes “utility.” For example, Rawls’ theory of justice is based in part on the notion that a just allocation of resources will give priority to the “worst off” members of society. These studies suggest that a large proportion of the general public feels that health care should be allocated in ways that help those in greatest need, such as patients with severe illnesses, rather than simply attempt to maximize overall utility.

Of course, there are other criteria of distributive justice besides need and utility. A study that complements ours in important ways, by Skitka and Tetlock, examined a number of these other allocation criteria. The authors asked subjects what criteria they thought would be most important in allocating transplantable organs. They presented them with transplant candidates who had two levels of need and two levels of efficiency, as well as differing levels of responsibility for their illness. “High need” was defined as 1% chance of surviving without transplant and “low need” was defined as 10% chance of surviving. “High efficiency” was defined as ten-year survival with transplant and “low efficiency” was defined as one-year survival with transplant. The subjects’ most important allocation criterion was personal responsibility for illness, followed by level of need, efficiency of transplant, waiting time, and contribution to society. In other words, given these two levels of need and efficiency, the subjects felt that need was more important than efficiency.

In contrast to their study, the present study examined public views of how resources should be allocated among children with equally severe life-threatening illnesses who differed only in their chances of benefiting from the resources. Thus, in our study, the subjects could not choose between patients on the basis of severity of illness, personal responsibility for illness, or personal contribution to society, nor could they allocate resources in a way that would give every patient the same outcome. We found that the majority of the subjects were reluctant to exclude a group of people from a health care resource simply because they would be less likely to benefit from it. Our study suggests several reasons for this reluctance.

First, allocation decisions were influenced by how well subjects understood how to use prognosis to maximize transplant survival. Those who understood how to maximize survival were much more likely to give all the organs to the better-prognosis group than were those who did not understand. This creates a problem in interpreting subjects’ responses. Many subjects who gave less than 100% of the organs to the better-prognosis group may have been acting in ways that they thought would maximize survival. Psychology research has shown that people often mistakenly think that they can maximize outcomes by “probability matching.” For example, Gal and Baron presented subjects with a series of dice rolls using a die with four green sides and two red sides. Each time the subjects correctly predicted the color of the roll, they would receive a reward. Many subjects guessed green two out of three times, failing to understand that the optimal strategy would be to guess green every time. This line of research may suggest an explanation for the gender differences we found in understanding. Gal and Baron found a gender difference similar to ours in their study; the difference in their study was eliminated only after controlling for the number of years of mathematics education among their subjects, a demographic characteristic we did not measure.

Second, subjects’ allocation decisions were influenced by whether the prognostic information was
used to rank patients as groups or as individuals. The subjects were more inclined to use prognostic information when it ranked patients as individuals rather than as groups. This greater inclination to use prognostic information for ranked individuals seems superficially inconsistent with the findings of Redelmeier and Tversky, who found that people give more weight to criteria of effectiveness when considering patients as a group versus as individuals. However, the contradiction is easily resolved. In their study, the subjects were asked in one scenario to make a policy applicable to all patients, and in another scenario to decide the management of a specific patient. Their results suggest that people think about group factors when making policies and individual factors when making clinical decisions. In our study, the subjects were never asked to make decisions about individuals, but were always asked to make policy decisions. Thus, our results do not contradict theirs.

Our results suggest that our subjects, in making policy decisions, thought differently about prognostic information when it was used to rank people as individuals than when it was used to place them into groups. There are at least two possible explanations for this. First, people may find it difficult to recommend policies that hurt whole groups of other people. Second, the subjects may have had more confidence in the prognostic information in the ranked-individual scenario, reasoning that any information that divides people into multiple risk levels is more accurate than information that places them into only two groups. Further work needs to be done to clarify this issue.

Our study has several limitations. First, Allegheny County residents are likely to have more exposure to transplant issues than are people in other locations, given the large size of the University of Pittsburgh transplant program. In fact, two of the respondents specifically stated that they worked in fields related to transplantation. Thus, our study population may not be representative of the general population. Nonetheless, prospective jurors are drawn from a diverse group of people. In addition, our study was designed as an experimental survey, not as a population study. It was more important to see how a specific group of people responded to a randomly distributed set of survey versions than to give the surveys to a perfectly representative sample of the population.

Second, the subjects may not have had strong preferences for any type of allocation scheme prior to our survey, and thus may have been sensitive to subtle ways in which we phrased the survey questions. Thus, we must be cautious about making any generalizations about how important our subjects felt prognosis should be in allocating transplantable livers. The scenarios we gave them were, as pointed out above, stripped of many important factors potentially relevant to organ allocation. We purposely stripped the scenarios of these criteria in order to focus on how different prognoses affected people’s allocation decisions. The tradeoffs involved in deciding who will receive a transplant are so complex that it would be hard to capture them in any one survey. In addition, as pointed out above, many factors that some people consider relevant, such as candidates’ social worth, have been soundly rejected by ethics and policy experts. For example, when dialysis was first shown to be a successful treatment for people with end-stage renal disease, there were not enough dialysis machines available. A committee in Seattle, a pioneering area in the early use of dialysis, was formed to decide which patients should get dialysis. The committee based allocation on criteria such as church attendance and level of volunteer work in the community. A thorough understanding of what general public thinks is important in allocating scarce health care goods would certainly show that a significant number of people think in ways similar to the Seattle committee. Because this way of thinking has been universally rejected by ethicists and policy experts, we designed a survey that would minimize its occurrence.

Third, by varying only the prognoses among the different survey versions, we ignored the fact that prognosis and urgency tend to vary between patients in an inverse relationship—as people get sicker and in more urgent need of transplants, their chances of surviving transplantation decrease.” In the real world, this is a very complex tradeoff, one that cannot be easily captured in a survey sent to the general public. Skitka and Tetlock began to approach this interaction, but, as pointed out above, varied need and efficiency over two points only. However, to the extent that need increases as prognosis decreases, it is likely that the general public would place less emphasis on prognosis in distributing organs, out of a sense that the neediest people deserve some priority.” This would only strengthen one of our main conclusions—that the public is not motivated purely by a desire to maximize the number of lives saved by transplantation, but is also motivated by concerns of fairness and equity.

To some, this may suggest that the public would support the UNOS allocation system, which does not factor prognosis into allocation of organs. While the UNOS point system does not factor prognosis into transplant allocation, transplant programs factor this into their decisions whether or not to list people for transplantation. Thus, for example, it is possible that many programs would not list patients who had only a 20% chance of surviving after receiving transplants. This raises an interesting question about
whether people would use different criteria to list candidates than they would to distribute organs to those already listed.

Conclusion

In our study, prognosis was important in determining how our subjects allocated transplantable livers. The subjects were also more likely to use prognostic information when it ranked candidates in terms of survival rather than categorizing them into two groups with different survival probabilities. However, the majority of subjects were unwilling to base allocation decisions purely on prognosis, even when the relative prognoses were very different. This suggests that health care policies based exclusively on maximizing the efficiency of achieving measurable outcomes will violate the values of a significant portion of the public. Acceptance of such policies requires either moderating the importance of prognosis in the policies or educating the public about the need to pay attention to outcomes.

The authors acknowledge David Asch, MD, MBA, and Neil Farber, MD, for commenting on early versions of the paper. They also thank Mark Kamlet, PhD, and Diane Lowenthal for helping with this work.

References

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 outcomes as reliably as this blood test.

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

Group 2 (100 patients): 70% chance of surviving if transplanted

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

Group 1: ________%
Group 2: ________%

TOTAL: 100%

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%

Suppose we could ignore the blood test and distribute the organs randomly to 100 children, regardless of their group. Should we do so? (circle one):

Yes   No

Now please imagine a different situation. Transplant specialists have compiled clinical information on each child awaiting transplant which allow us to judge how likely each is to survive if transplanted. With this information we can rank all 200 children, from the child who is most likely to survive if transplanted (80% chance) to the child who is least likely to survive (70% chance).

Do you think we should use this information to decide who will receive a transplant, or should we ignore the information? (check one):

Use information ________    Ignore ________