Public Preferences for Efficiency and Racial Equity in Kidney Transplant Allocation Decisions

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BECAUSE there are not enough cadaveric kidneys available for transplantation, the transplant community has devised a point system to allocate available organs.[1,2] Patients in need of a transplant are placed on a waiting list and accumulate points on the basis of waiting time, presensitization status, age (if less than 18 years old), and antigenic similarity to the donor.[3] In general, organs are given to the patient in the local area of the donor who has the highest number of points, except in cases where a recipient can be found who is a complete antigen match with the donor.

In theory, the point system is a paradigm of fair rationing. It shuns dubious rationing criteria such as religion, gender, or social worth, and relies instead on explicit clinical criteria. Nonetheless, the point system has been criticized because, in practice, its emphasis on antigen matching puts African-American transplant candidates at a competitive disadvantage. African-Americans who receive kidneys wait, on average, twice as long as Caucasians.[4,5] They wait longer, at least in part, because the proportion of African-Americans on the waiting list is significantly higher than the proportion of kidneys donated by African-Americans,[6] and because antigenic types (HLA antigens) are distributed differently among racial groups.[7] As a result, fewer than 4% of "complete antigen matches" (those kidney transplants where donor and recipient match on all six major HLA antigens) go to African-Americans.[5]

Antigen matching was incorporated into the allocation system to increase the chance that the transplanted kidneys would function without being rejected. One year after transplant, 80% of completely matched kidneys are likely to be functioning compared to 74% of partially matched kidneys.[8] According to Elster,[9] the effect of antigen matching on racial access to kidney transplantation was an unintended and unforeseen consequence; antigen matching was not included in the point system in order to hurt blacks or to help whites, but rather had effects on these groups secondarily.

These secondary effects have generated much debate. Critics of the point system argue that it should be revised to decrease the emphasis on antigen matching, thereby assuring a more equitable allocation of organs.[10] Defenders of the system counter that kidneys are such a scarce resource that everything should be done to maximize transplant success.[11,12]

Missing from this debate is the public's point of view. This debate depends both on medical facts (eg, the magnitude of the relationship between antigen matching and transplant success) and social values (eg, how much inequity to tolerate in order to maintain an acceptable success rate). Although medical experts are able to provide relevant facts, it is not necessarily appropriate for experts' *values* to play a central role in policy development. Social judgment theorists argue that the domain of values belongs instead to the public and the public's elected representatives.[13,14] Transplantable kidneys are a scarce *public* good. Transplants are financed by the public through insurance premiums and taxes, and the public will ultimately have a say in how its resources are used. Moreover, the success of the transplant system depends on the willingness of the public to donate organs. A transplant system that violates public values may risk losing prospective donors. For these reasons, we need to learn more about the public's values to see if they coincide with our present allocation system.

Unfortunately, measuring public attitudes toward kidney allocation is difficult. The trade-off between transplant efficiency and waiting time equity raises racially charged issues. Describing how the point system affects different racial groups creates footholds for personal biases. For example, racial groups favored by the current allocation criteria might be more likely to think that the criteria are fair.

In this study, we explored public attitudes toward the trade-off between transplant efficiency and waiting time equity and examined whether people's attitudes toward this trade-off are influenced by the identities of the affected groups.

METHODS

Subjects

We surveyed 380 people assigned to jury duty at the Philadelphia County Courthouse in Philadelphia, Pennsylvania. In this county, potential jurors are selected from voter registration records. Subjects were recruited by announcing in the juror waiting room that those who completed a survey would receive a candy bar.

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Dr Ubel is a Measey Foundation Faculty Fellow. Dr Asch is the recipient of a Department of Veterans Affairs Health Services Research and Development Service Career Development Award.

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0041-1345/96/$3.00/+0

Survey Design

The survey was modified from one successfully used in previous studies.[15-17] Subjects were given information about the role of transplantation in the treatment of end-stage renal disease. They were told of the shortage of kidneys available for transplant and that one factor used in distributing kidneys is the likelihood that a kidney transplant will be successful.

By random allocation, subjects received one of four survey versions. The four versions varied in the characteristics of recipient groups and the reason for the groups' different success rates. Subjects were told this information was hypothetical. The hypothetical information was varied across survey versions to test how different ways of framing trade-offs between efficiency and equity influenced people's allocation choices.

Blood Type Version. In the Blood Type version, subjects were told that antigen matching is an important predictor of transplant outcomes:

> All else equal, kidney transplants are more likely to succeed if they are transplanted into patients who 'match' the kidney donor. The number of successful transplants one year after transplant is eight out of ten for patients with a *complete match* and seven out of ten for patients with a *partial match.*

Subjects were then asked to distribute one hundred available kidneys among two hundred transplant candidates: one hundred people with blood types A and AB (who were predicted to have an 80% chance of successful transplant with these kidneys) and one hundred people with blood types B and O (who were predicted to have a 70% chance of successful transplant with these kidneys). Subjects were told that:

> Those patients who do not get kidneys now will have to wait until more kidneys become available. Those people with blood types A and AB who do not get transplanted will have to wait an average of nine months and those people with blood types B and O not transplanted will have to wait an average of eighteen months.

Caucasian Version. Subjects receiving the Caucasian version were also told that antigen matching is an important predictor of transplant outcomes. However, subjects were told that, because antigen matching is used to help decide who gets available kidneys, Caucasians are more likely to get transplanted than African-Americans. As with the Blood Type survey, subjects were asked to distribute one hundred organs among two hundred patients (100 Caucasians and 100 African-Americans) based on this information. Subjects were reminded that patients with worse prognoses also had longer waiting times.

African-American Version. The African-American version was identical to the Caucasian version except that the effect of antigen matching on Caucasians and African-Americans was reversed. Subjects were told that antigen matching favors African-Americans over Caucasians.

Socioeconomic Version. In the Socioeconomic version, subjects were not told any information about antigen matching, but instead were told that differences in transplant outcome were due to socioeconomic factors:

> Imagine that kidney transplants are more likely to succeed if they are transplanted into Caucasian patients than if they are transplanted into African-American patients. The number of successful transplants one year after transplant is eight out of ten for Caucasians and seven out of ten for African-Americans. This difference cannot totally be explained by 'biological' factors, but also occurs because African-Americans are less likely to live a convenient distance from hospitals and clinics where they can buy medicines and receive care for their transplants.

In all survey versions, subjects were also asked to explain why they chose to distribute organs in the way they did, and to indicate what distribution of kidneys to people in the two groups of patients would result in the largest number of successful transplants.

Table 1. Demographic Characteristics

Number of subjects	380
Percentage Male	53
Percentage Caucasian	56
Percentage African-American	34
Mean age	41
Mean years of education	14

Data Analysis

Demographic variables were compared across survey versions using multiple regression for continuous variables and logistic regression for dichotomous variables. In each analysis the independent variables were a set of orthogonal contrast codes (described below) distinguishing among survey versions.

The primary dependent variable was the proportion (P) of kidneys allocated to the group with the better prognosis. The proportion of kidneys allocated to this group was first compared across survey versions using the Kruskal-Wallis Test. Then, a more detailed analysis of subjects' allocation choices was performed using a set of three orthogonal contrast codes designed to distinguish among the survey versions.[18] The first contrast compared the Blood Type version to the other three versions, in which the two patient groups were of different races. The second contrast compared the two race versions in which success depends on antigen matching (Caucasian and African-American) to the race version in which success depends on socioeconomic factors (Socioeconomic). The third contrast compared the Caucasian version, in which antigen matching favors Caucasians, to the African-American version, in which antigen matching favors African-Americans. Demographic variables were also added to the regression model as predictors of P. Subjects' written explanations of their allocation decisions were coded independently by two research assistants. Discrepancies were resolved by one of the authors (PAU).

RESULTS

Subject Characteristics

Three hundred and eighty subjects filled out surveys. Their characteristics, shown in Table 1, did not differ across survey versions. Because of missing data, not all results reported here total 380.

Allocation Decisions

Table 2 shows subjects' allocation decisions in each of the survey versions. Across all survey versions, the most common allocation strategy (233 subjects; 61.3%) was to distribute the organs in an egalitarian manner. In effect, these people showed no preference toward giving organs to those

Table 2. Subjects' Allocation Decisions

Survey Version	Majority of Organs to Worse Prognostic Group	Equal Number of Organs to Both Groups	Majority of Organs to Better Prognostic Group
Blood type (n = 87)	10*	49	40
Caucasian (n = 106)	8	62	30
African-American (n = 96)	17	55	28
Socioeconomic (n = 91)	11	78	11
Total (n = 380)	11	61	27

*Row values are presented as percentages, which do not always total 100 due to rounding.

with better prognoses or those with longer waiting times. The second most common allocation strategy, chosen by 104 subjects (27.4%), was to give more than half of the organs to the group with the better prognosis. These subjects' allocation decisions reflect a preference for maximizing transplant effectiveness compared to equalizing transplant waiting times. However, only 17 subjects (4.5%) gave all 100 organs to the better prognostic group, the distribution that should maximize the number of successful transplants. Forty-three subjects (11.3%) gave more than half of the organs to the group with the worse prognosis (and longer expected waiting time). These subjects, in essence, acted as if the 10% difference in success rate was not as important as equalizing the waiting times between the two groups. Subjects' allocation decisions were not influenced by their gender, education, or age ($F < 1$ for all) and the effect of race on allocation decisions was only marginally significant ($F(1,202) = 1.80$, $P = .073$).

Although the most popular allocation decision for all survey versions was an equal distribution of organs, there were significant differences in how subjects allocated organs across the four survey versions (Kruskal-Wallis $H = 13.71$, $P = .003$). The first contrast, comparing the Blood Type version to the other survey versions, showed that subjects were more likely to allocate organs to the better prognostic group when recipient groups differed by blood type rather than race ($F(1,376) = 5.55$, $P = .019$). The second contrast, comparing the African-American and Caucasian versions to the Socioeconomic version, showed that when recipient groups differed by race, subjects were less likely to favor the better prognostic group when the prognostic differences were due to socioeconomic factors ($F(1,376) = 7.64$, $P = .006$). The third contrast, comparing the Caucasian version and African-American version, showed no differences between them ($F < 1$).

Beliefs About Maximizing Transplant Success

When asked what distribution of organs would maximize the number of successful transplants, only 69 subjects (18.2%) correctly responded that giving all of the organs to the better prognostic group would maximize overall transplant outcomes. Among those who understood how to maximize outcomes, 34 of 69 subjects (49.3%) gave more than half of the organs to the better prognostic group. In contrast, 70 out of 311 subjects (22.5%) who gave incorrect answers to the maximization question allocated the organs this way. Race and level of education were significant predictors of whether subjects answered the maximization question correctly, with Caucasians and more educated subjects more likely to answer correctly ($P < .0001$ for both).

Tests for Effects of Self-Interest

Although race had no direct effect on organ allocations across survey versions, it is possible that subjects might allocate more organs to their own race. Because there are no survey versions involving races other than African-American or Caucasian, testing this hypothesis was possible only among subjects of these races. Subjects did not favor members of their own race in an overt fashion ($F < 1$). Instead, as shown in Table 3, Caucasians responded almost identically to the Caucasian and African-American survey versions, with a trend toward favoring African-Americans more than themselves. African-Americans also responded similarly to the Caucasian and African-American survey versions. In the Socioeconomic versions, it appears that Caucasians were more likely to favor the better prognostic group than African-Americans, but the numbers are too small for this to reach statistical significance.

Subjects' Explanations of Their Allocation Decisions

Subjects' explanations of their allocation choices are shown in Table 4. Subjects were not limited to one explanation, and indeed many gave multiple reasons for their allocation decisions. As can be seen, subjects' explanations varied depending on the proportion of organs they gave the prognostic group. The most common explanation given by subjects who distributed organs equally between the two groups was that they were attempting to be equitable. For example, one subject wrote "Each person should have an

Table 3. Effect of Race on Allocation Decisions

Survey Version	Respondents' Race	Majority of Organs to Worse Prognostic Group	Equal Number of Organs to Both Groups	Majority of Organs to Better Prognostic Group
Caucasian	Caucasian	7*	60	33
	African-American	8	67	26
African-American	Caucasian	17	51	32
	African-American	18	61	21
Socioeconomic	Caucasian	4	77	19
	African-American	21	76	3

*Row values are presented as percentages, which do not always total 100 due to rounding.

equal chance at getting a transplant regardless of the chance of success." Other arguments grouped under the equity heading included those who argued strongly that organs should be distributed on a "first-come first-served basis"—a distribution that essentially is equivalent to a 50/50 split of the organs. Finally, some subjects made slightly more complicated equity arguments. For example, one subject wrote "Uneven distribution [of organs] would perpetuate today's uneven distribution of resources."

Another common reason for distributing the organs equally between the two groups was that some subjects did not believe the prognostic prediction, as one subject stated, "The statistics mean nothing! It is chance! There is no biological factor to substantiate the 80%/70% stats!" Or, as another subject said, "It is my belief that none of us really knows exactly which group would have a better chance as none of these is really in 'our' control." A similar justification for distributing the organs equally was a feeling that the prognostic difference between the two groups of candidates was too small to affect allocation. As one subject stated, "Without more detailed stats the percentage is not of a wide enough margin to warrant anything but an equal distribution of kidneys."

Of those who gave more than half of the organs to the better prognostic group, the predominant explanation was simply that it was important to maximize transplant success rates. As one subject stated, "Why waste a kidney with a 10% greater chance for success in one group?" Many who gave slightly more than half to the better prognostic group also mentioned issues of equity as being important in preventing them from giving all the organs to the better prognostic group.

Finally, of those who gave a majority of the organs to the worse prognostic group (the group with the longer predicted waiting times), the most common explanation was summed up in one person's comment: "The additional wait for blacks outweighs the slightly higher success rate for whites." Others who received survey versions in which African-Americans had longer waiting times specifically mentioned past and current examples of discrimination in the United States.

DISCUSSION

We faced subjects with a trade-off between maximizing transplant outcomes and equalizing transplant waiting times. The trade-off was similar in magnitude to the real trade-off facing the transplant community, except that the benefits of antigen matching were slightly exaggerated. Nevertheless, the 10% improvement in 1-year graft survival was not enough in most subjects' minds to justify giving priority to those with better prognoses. Instead, the majority of subjects allocated available organs in an egalitarian manner.

Several moral considerations motivated this tendency toward egalitarianism. Most often, it was expressed as a feeling that all people deserve an equal chance at receiving an organ regardless of their prognosis or race. Less often, it arose from a feeling that the difference in outcomes between the two groups of patients was not large enough to

Table 4. Explanations of Allocation Decisions

Explanations of Allocation Decisions*	Majority of Organs to Worse Prognostic Group	Equal Number of Organs to Both Groups	Majority of Organs to Better Prognostic Group	Total
Equity	13†	177	31	221
Efficiency	2	6	66	74
Small prognostic difference	5	29	5	39
Equalize wait time	31	9	1	41
Do not believe prediction	3	14	4	21
Other	8	18	16	42

*Not all subjects provided explanations, while others provided more than one explanation.
†Values represent number of subjects providing each explanation.

justify giving preference to one group of patients over another. It also arose from a disbelief in the prognostic prediction on the part of some subjects. Finally, a smaller number of subjects stated that they had chosen an egalitarian distribution because they were uncomfortable with the effects that antigen matching had on racial equity.

Although the most popular allocation strategy was to divide organs equally between the two recipient groups, a substantial minority of subjects gave a majority of the organs to the better prognostic group. For these subjects, the desire to maximize transplant success was more important than the desire to equalize transplant waiting times.

Although subjects in all survey versions tended to favor an egalitarian distribution of organs, differences in allocation choices across versions were also important. In particular, mentioning race affected people's desires to maximize transplant success. When the issue was framed in a neutral manner, as in the Blood Type version, subjects were more inclined to distribute organs in a way that would maximize transplant success. However, when faced with the racial consequences of this distribution scheme, as in the other three versions, subjects were less inclined to maximize transplant success. Indeed, it mattered less *which* race was favored than that *any* race was favored. Our data suggest that people were not inclined to favor members of their own race. Although this result might reflect implicit demands to provide socially appropriate responses, it is important that subjects' allocations were not biased in a self-interested manner.

These findings need to be interpreted with caution. First, responses to the survey were affected by subjects' inability to know how to use prognostic information to maximize transplant success. This result is consistent with prior research showing that people do not generally recognize how to maximize outcomes in probabilistic tasks.[19,20] Previous work using survey instruments similar to the one in this study has confirmed that this difficulty influences decisions in organ allocation tasks.[15,16] In the present study, subjects showed an alarming inability to maximize transplant success. In part, this may have been due to subjects' confusion regarding the maximization question. For example, a number of subjects who incorrectly answered the maximization question explained their answer by writing that it would not be fair to give all the organs to the better prognostic group. This suggests that some subjects' maximization responses were influenced by their notions of fairness. Subjects' ability to answer the maximization question correctly may also have been influenced by the small difference in prognosis between the two transplant groups. In a previous study, we found that as the prognostic difference between two transplant groups decreased, respondents were less likely to know how to maximize correctly.[15]

Second, the issues involved in kidney transplant allocation are complex and difficult to explain in a written survey. We had to simplify information so that subjects could absorb it. Nonetheless, we are confident that most subjects grasped the crucial trade-off question. We performed extensive pretesting of the survey and found that most people were able to explain the trade-off in ways that indicated an understanding of the basic choice. In addition, subjects' written responses to the final survey showed a reasonable understanding of the trade-off.

Third, although our description of the prognostic difference gained by antigen matching slightly exaggerated its benefits, these benefits may have sounded even more significant if framed another way. For example, the estimated half-life of kidney transplant is 17.3 years for perfectly matched kidneys and 7.8 years for partial matches.[11] It is possible that subjects' allocation preferences would have changed if we had framed the information this way. In fact, in a previous study, we found that as the prognostic difference between two liver transplant groups increased, so did the likelihood that subjects would allocate organs to the better prognostic groups.[16] This confirms that subjects will allocate organs on the basis of prognosis, at least to some extent. However, over a quarter of subjects chose to distribute organs equally between the two liver transplant groups even when one group had an 80% chance of survival with transplant and the other had only a 20% chance.[15] This suggests that even if the prognostic difference between the two groups of kidney transplant candidates was said to be somewhat larger, many would still have favored an equal distribution of organs.

Fourth, prognostic differences between African-Americans and Caucasians may not be due solely to antigen matching but may also be affected by other factors. We addressed this in the survey by presenting a vignette in which these prognostic differences were blamed on socioeconomic factors such as access to hospital care. In this survey version, subjects were quite disinclined to base allocation on prognosis. However, we could have framed this vignette in another way that may have affected subjects' allocation choices. For example, if we had stated that one group of patients' outcomes were worse than another's because the patients were not compliant with their medical regimens, people may have viewed this as being the patient's fault.

The present study contributes to a growing literature that highlights the importance that people place on equality in distributing scarce health care resources. In a Norwegian study, for example, Nord[21] showed that people are reluctant to favor one group of patients over another, even when that group is expected to benefit much more from receiving the scarce resources. In a survey of Norwegians and Australians, Nord et al[22] found that many people are willing to make sacrifices in terms of the number of people benefiting from health care in order to give resources to people in need of expensive treatments. In the United States, we have found that people are willing to let others die of colon cancer in order to assure a more equitable distribution of colon cancer screening resources.[23] In other work, we have found that people are willing to give up health care benefits in order to be fair to groups, even when group membership

is arbitrary.[24] Given these studies, it is unlikely that the results of the present survey are unique to the framing of this specific survey. Instead, the results confirm that many members of the general public place a large value on equity in distributing health care resources, even when this will lead to a less efficient use of the resources.

CONCLUSION

When asked to distribute organs among transplant candidates, a majority of people felt that small differences in outcome, such as those between complete and partially matched kidney transplants, do not justify allocation policies that create significant discrepancies in waiting times for transplant candidates. This was true regardless of whether the transplant candidates were identified by race or blood type, and whether policies were said to favor African-Americans or Caucasians. In fact, the small differences we found across survey versions were overwhelmed by people's desires to give everyone a fair chance at transplant.

Experts are clearly divided about whether the kidney transplant system places too much emphasis on efficiency compared to equity. Our survey shows that the public, too, is divided, but that a large majority are likely to favor a policy that distributes organs equally among patients regardless of prognosis. The small difference in outcome between complete matches and partial matches may not justify, in the majority of people's minds, a policy that leaves one group of patients waiting twice as long as another. The transplant system would better represent public values by placing a greater emphasis on waiting time.

ACKNOWLEDGMENTS

We are grateful to Christine Weeks and Katy O'Neill for research assistance and to the many prospective jurors who participated in this study. We thank Jonathan Merz, JD, PhD, for comments on an earlier draft of this paper.

REFERENCES

1. Starzl TE, Shapiro R, Teperman L: Transplant Proc 21:3432, 1989

2. Singer PA: Arch Intern Med 150:523, 1990

3. UNOS: Articles of Incorporation. UNOS. 1995

4. Kusserow RP: The Distribution of Organs for Transplantation: Expectations and Practices. Office of Inspector General, Department of Health and Human Services, 1991

5. Ayres I, Dooley LG, Gaston RS: Vanderbilt Law Review 46:805, 1993

6. Lazda VA, Blaesing ME: Transplant Proc 21:1415, 1989

7. Milford EL, Ratner L, Yunis E: Transplant Proc 19(suppl 2):30, 1987

8. Held PJ, Kahan BD, Hunsicker LG, et al: N Engl J Med 331:765, 1994

9. Elster J: Local Justice: How Institutions Allocate Scarce Goods and Necessary Burdens. New York: Russell Sage Foundation, 1992

10. Gaston R, Ayres I, Dooley LG, et al: JAMA 270:1352, 1993

11. Takemoto S, Terasaki PI, Cecka JM, et al: N Engl J Med 327:834, 1992

12. Takemoto S, Terasaki PI, Gjertson DW, et al: N Engl J Med 331:760, 1994

13. Adelman E: In: Brehmer B, Joyce C (eds): Human Judgment: The SJT View. Amsterdam: Elsevier, 1988

14. Hammond K, Harvey L, Hastie H: Psychol Sci 3:80, 1992

15. Ubel PA, Loewenstein G: Med Decis Making (in press)

16. Ubel PA, Loewenstein G: Social Sci Med (in press)

17. Ubel PA, Loewenstein G: Health Policy 34:145, 1995

18. Judd C, McClelland G: Data Analysis: A Model–Comparison Approach. New York: Harcourt Brace Jovanovich, 1989

19. Gal I, Baron J: Cognit Instruct (in press)

20. Siegel S, Goldstein D: J Exp Psychol 57:37, 1959

21. Nord E: J Med Ethics 19:37, 1993

22. Nord E, Richardson J, Kuhse H, et al: Who cares about cost?: Does economic analysis impose or reflect social values? National Centre for Health Program Evaluation (submitted)

23. Ubel P, DeKay M, Baron J, et al: N Engl J Med (in press)

24. Baron J: J Behav Decis Making 8:71, 1995