

more individually tragic results at a later stage (e.g., death), but not rationing can be just as much the failure of a group to accommodate individual choice as rationing is when good-faith dissenters prefer to pay more.

We must remember that autonomy, not just aggregate efficiency, is one of the values that supports selective rationing. Some dimensions of rationing will always remain morally suspect, but rationing's fundamental conflict with respect for the individual patient-subscriber is not as severe or intractable as most people assume.

NOTES

1. P. Menzel, *Strong Medicine: The Ethical Rationing of Health Care* (Oxford University Press, New York, N.Y., 1990), Chapters 1 and 2, especially pp. 10-15.
2. On the conditional moral legitimacy of presuming a person's consent, see Menzel, *supra* note 1, pp 22-36.
3. QALY is pronounced to rhyme with "holly." Such a unit has also been referred to as "well-years" or "health state utilities."
4. D. Hadorn, "The Oregon Priority-Setting Exercise: Quality of Life and Public Policy," *Hastings Center Report* 21 (3): 11 suppl. (May-June, 1991). . . .
5. 8.0 QALYs for \$60,000: 2.0 QALYs more than 6.0 produced by dialysis.
6. J. Harris, "QALYfying the Value of Life," *Journal of Medical Ethics* 13: 117 (1987). . . .
7. Or how many people in a better state of illness would have to be cured for one to think the situation better than curing a smaller number of patients in a worse-off condition? . . .
8. I now think that this QALY bargain is not what we are confined to if we use the Equivalence of Numbers questions (now in the literature called Person Trade-Off questions) to elicit numerical rankings.
9. J. Harris, "More and Better Justice," in J. Bell and S. Mendus, eds. *Philosophy and Medical Welfare* (Cambridge University Press, Cambridge, England, 1988), at p. 87.
10. Menzel, *supra* note 1, p. 89
11. Harris, . . . *ibid.*
12. M. O'Donnell, "One Man's Burden," *British Medical Journal* 293 (6538): 59 (July 5, 1986). . . .
13. Menzel, *supra* note 1, pp. 116-128. . . .
14. Menzel, *supra* note 1, pp. 119-126. . . .
15. A sophisticated version of this argument has been articulated by N. Daniels, *Just Health Care* (Cambridge University Press, Cambridge, 1985). . . .
16. The larger point here about rationing care for the poor in the light of our government's larger Medicare and tax subsidy support for the non-poor is made by C. Dougherty, "Setting Health Care Priorities: Oregon's Next Steps," *Hastings Center Report* 21 (3): 1 suppl. (May-June, 1991). As to the 40 percent figure, note that employer-paid premiums are excluded entirely from taxable income: from the employee's 15-33 percent federal income tax and 7.8 percent Social Security tax, from the employer's 7.8 percent Social Security match, and from any state and local income taxes.
17. Hadorn, *supra* note 8, p. 11 suppl.

Fairness in the Allocation and Delivery of Health Care: A Case Study in Organ Transplantation

James F. Childress

Several cases in the last few years have stirred rumblings of distrust in the process of selecting recipients of scarce organs for transplantation. Mickey Mantle's rapid liver transplant, which came shortly after he was put on the waiting list in June 1995,

because of end-stage liver failure secondary to cirrhosis and cancer, was only the most recent. In 1993 Governor Robert P. Casey of Pennsylvania, age sixty-one, received an experimental and risky heart-liver transplant at the University of Pittsburgh Medical Center because his hereditary disease, amyloidosis, had caused his liver to produce an abnormal protein that then accumulated in the walls of his heart. Even though his medical team had expected a wait of four to six weeks, the thirteen-hour

James F. Childress, "Ethical Criteria for Procuring and Distributing Organs for Transplantation," in *Practical Reasoning in Bioethics* by James Childress, Indiana University Press, 1977. Reprinted with permission from the publisher.

operation commenced just hours after his name had been entered onto the waiting list at the United Network for Organ Sharing (UNOS), the national organ transplantation and procurement network. . . .

SELECTION OF RECIPIENTS OF SCARCE ORGANS FOR TRANSPLANTATION

The scarcity of organs for transplantation will probably remain a problem for the indefinite future; indeed, it is probable that the demand will always exceed the supply, unless animal organs can be used or artificial organs can be developed. Under these circumstances, there will be difficult questions regarding the procedural and substantive standards for patient selection. Who should choose recipients of donated organs and by what criteria?

DONATED ORGANS AS PUBLIC RESOURCES

Why not simply let the physicians, nurses, and others involved in transplantation select patients? Why shouldn't selection be viewed as a medical decision to be made by the appropriate professionals? There are some important reasons for developing general public criteria of patient selection—criteria that are developed with input from the public and publicly stated and defended. Apart from special cases—for example, when living donors of kidneys designate a recipient or beneficiary—it can be argued that, from a moral standpoint, donated organs belong to the public, to the community. This fundamental conviction undergirded the Task Force's deliberations and recommendations regarding fair access to organ transplantation: Donated organs should be viewed as scarce public resources to be used for the welfare of the community. Organ procurement and transplant teams receive donated organs as trustees and stewards for the community. Their dispositional authority over those organs should be limited and constrained.

There is increasing demand that the public participate in formulating the criteria for patient selection in order to ensure that they are fair. In general, the evidence presented to the Task Force and published since then indicates that organ procurement and transplantation teams usually make morally responsible decisions in allocating and distributing organs. However, some widely publicized exceptions have

generated public controversy and perhaps even reduced organ donations—some of these appeared to the public to reflect favoritism to wealthy foreign nationals. The demand for public participation in the formulation of criteria for the allocation and distribution of organs stems in part from the nature of the organ procurement system—it depends on voluntary gifts by the public, that is, by individuals and their families, to the community. Indeed, there are important moral connections between policies of organ procurement and policies of organ distribution. On the one hand, it is obvious that the success of policies of organ procurement may reduce scarcity and hence obviate some of the difficulties of patient selection. On the other hand, distrust is a major reason for public reluctance to donate organs, and policies of procurement may be ineffective if policies of distribution are perceived by the public to be unfair and thus untrustworthy. Hence public participation—for example, in UNOS—is important. "Organ allocation falls into the region of public decision-making," as Jeffrey M. Prottas insists, "not medical ethics and much less medical tradition."¹ . . .

JUSTICE AND MORALLY RELEVANT AND IRRELEVANT CHARACTERISTICS

Justice not only involves public participation—a matter of fair process—but also substantive standards. "Justice" may be defined as rendering each person his or her due, and it includes both formal and material criteria. The formal criterion of justice is similar treatment for similar cases, while material criteria specify relevant similarities and dissimilarities among patients and thus determine how particular benefits and burdens will be distributed.² There is debate about the *moral relevance* and *moral weight* of various material criteria, such as need, merit, societal contribution, status, and ability to pay. Different theories of justice tend to accent different material criteria; however, some criteria may be acceptable in some areas of life but not in others.

A fundamental issue for organ transplantation is determining which material criteria are justifiable for the allocation and distribution of donated organs. Standards of justice permit rationing under conditions of scarcity, but they rule out selection criteria that are based on morally irrelevant characteristics, such as race or gender. The major debates focus on which characteristics of patients are moral-

ly relevant and which are morally irrelevant in the two stages of selection for organ transplantation: (1) formation of a waiting list, and (2) distribution of available organs to patients on the waiting list.

WAITING LISTS: PROBLEMS IN ADMISSION

There is general agreement that the waiting list of candidates for transplantation should be set largely according to medical criteria, i.e., the need for and the probability of benefiting from an organ transplant. There is, of course, debate about whether these medical criteria should be defined broadly or narrowly (for example, how high should we set the standard for minimal efficacy?), about how to specify these criteria, about the relevance of several different factors to the determination of need and efficacy, and about which criteria should have priority in case of conflict.

Why are both need and probability of success important? They reflect *medical utility* which requires the maximization of welfare among patients suffering from end-stage organ failure. Medical utility should not be confused with *social utility*.³ While social utility focuses on the value of salvageable patients for society, medical utility requires that organs be used as effectively and as efficiently as possible to benefit as many patients as possible. For example, if there is no reasonable chance that a transplant will be successful for a particular patient, it could even be unethical to put the patient in line to receive a scarce organ.

Efforts are made through UNOS and elsewhere to develop fair policies for allocating and distributing organs to patients on waiting lists, but it is more difficult to ensure equitable access to waiting lists for organ transplants. There is evidence that women, minorities, and low-income patients do not receive transplants at the same rates as white men with high incomes.⁴ For example, in one study, females were approximately 30 percent less likely than males to receive a kidney transplant, black dialysis patients were only 55 percent as likely as white dialysis patients to receive a cadaver transplant, and patients receiving dialysis in units in higher income areas had higher transplant rates. A primary source of unequal access appears to be in the decisions about who will be admitted to the waiting list rather than in the decisions about who will receive donated organs (although the waiting times may be quite

unequal). Serious questions were raised, for instance, about the admission of Mickey Mantle to the liver transplant waiting list, even though there is no reason to believe that his selection from the waiting list was unfair. However, more research will be required to determine the extent to which unequal access to kidney transplantation, for example, hinges on patient choices and legitimate medical factors rather than on physician sequestration of patients in dialysis units, physician failure to inform and refer some groups of patients, or physician bias in the selection of patients seeking admission to waiting lists. . . .

UNOS POINT SYSTEM FOR CADAVERIC KIDNEYS

Although UNOS has developed computerized point systems for the allocation of hearts, livers, and kidneys, I will use the point system for kidneys as the primary example because it has received the most attention and has undergone major alterations in light of conflicting values. In October 1987, UNOS implemented a point system for cadaveric kidneys, based on a proposal by Thomas E. Starzl and colleagues.⁵ This system required that cadaveric kidneys be offered to patients on the local waiting list (defined as either the individual transplant center recipient list or a shared list of recipients within a defined procurement area) in descending order, with the patient with the highest number of points receiving the highest priority. The original point system consisted of three major parameters: the degree of sensitization, reflected in panel reactive antibodies (PRA, ten points maximum), time on the waiting list (ten points maximum), and HLA matching (twelve points maximum), with some attention to logistics and urgency. Critics noted that the point values for time waiting and high PRA overrode all other point allocations so that the first patient to appear on the print-out had high PRA levels but poor HLA matches. And most of the requests for area variances involved PRA and antigen match.

After much discussion, UNOS in 1989 adopted a revised point system that stressed HLA matching because of evidence about its long-term impact on graft survival. This revised point system accorded less weight to sensitization and to time on the waiting list, as well as to logistics and urgency.

According to the UNOS policy statement, "for the national pool, the new allocation system will ensure optimal use of every cadaver kidney offered, since it will identify very well matched recipients. Highly sensitized patients will be chosen when excellent matches emerge. Kidneys will be shipped to highly sensitized patients generally only when negative crossmatches had [sic] been obtained at the donor center. Within each match category fractions of a point acquired for waiting time will determine the order in which patients with the same match score would be listed.⁶ Medical urgency status could be requested under some circumstances, but it is rare because dialysis is usually possible as a backup. The policy of mandatory sharing of zero antigen mismatches continued, and a payback policy was adopted for centers receiving organs that had to be shared. ABO blood-group matching remained the same—blood group "O" kidneys could be transplanted only into blood group "O" patients except in the case of kidneys that were mandatorily shared because of HLA match; otherwise "O" patients would be greatly disadvantaged because "O" organs are usable in other blood groups, whereas "O" patients can only use "O" organs.

Another major change occurred in 1995 when the point system for kidney transplants was revised to increase the number of kidneys allocated by waiting time alone, thereby reducing the reliance upon certain HLA matches. Research had indicated that zero ABDR mismatched kidneys have a graft survival as high as kidneys with a six-antigen match, while the graft survival of kidneys with zero AB and three BDR mismatch levels are not significantly better than unmatched grafts. Thus, the UNOS board decided to mandate sharing of all zero mismatched kidneys but to eliminate points at the zero AB and three BDR mismatch levels and to assign seven points for zero BDR mismatches, five points for one BDR mismatch, and two points for two BDR mismatches. As a result of this shift in the point system, UNOS projected that the number of kidneys allocated by waiting time alone would increase from approximately 10 percent to approximately 40 percent. The remainder would be allocated according to a mix of HLA matching, waiting time, PRA, and age (with additional points given for young people, in a policy that will be discussed below).

ASSESSMENT OF POINT SYSTEMS FOR ALLOCATING ORGANS

How are such point systems to be assessed? I will first consider the value of computerized point systems in general and then the value of particular point systems. Many of the supposed advantages and disadvantages of point systems for the allocation of organs hinge on their alleged *objectivity*. Even though a point system does not eliminate the individual physician's judgment—the art of medicine—regarding, for example, the final decision about the use of an organ for any particular patient, it does reduce the physician's discretion. For example, Thomas Starzl contends that "the effect of [his original] point system was to diminish judgmental factors in case selection, which in the past probably had operated to the disadvantage of 'undesirable' potential recipients, including older ones and possibly ethnic minorities.⁷ Even though many concede that some decisions have certainly been affected by physicians' subjective biases—for example, in admission to waiting lists—many also stress that it is important for physicians to be able to practice the art of medicine in view of the individual features of particular cases, such as predicting efficacy for a particular patient. According to Daniel Wikler, a computerized point system can systematize decision making by focusing on a full range of data and "can convince patients and the public that a routine, sound plan is in place," perhaps enhancing perception of fairness in distribution or at least stimulating public discussion.⁸ However, in focusing on objectivity, we must not forget that the selection and assignment of weights (points) to these factors rest on values.

With the exception of time on the waiting list, the criteria used in the different point systems for kidneys are medical in the sense that they involve medical techniques used by medical personnel and arguably influence the likely success or failure of the transplant. However, while medical in these senses, these criteria are not value free or value neutral. The vigorous debate about how much weight each criterion should have is only in part technical and scientific (e.g., the impact of HLA matching); it is to a great extent ethical. In kidney transplantation, some factors, such as quality of antigen match and logistical score, focus on the chance of a successful outcome; in different ways

both medical urgency and panel-reactive antibody focus on patient need; and time on the waiting list introduces a nonmedical factor, even though it may overlap with panel-reactive antibody because sensitized patients tend to wait longer for transplants. The points assigned to these various factors thus reflect value judgments about the relative importance of patient need, probability of success, and time of waiting—all factors stressed by the federal Task Force on Organ Transplantation.

MEDICAL UTILITY IN PATIENT SELECTION

Both patient need for a transplant and the probability of a successful transplant reflect medical utility. Medical utility is not necessarily at odds with fairness, even though they sometimes come into conflict. It is a fundamental mistake to suppose that "medical utility" and "fairness" are necessarily in tension so that if one is met the other is infringed, and it is a fundamental mistake to suppose that "fairness" always dictates priority to queuing or randomization over "medical utility." Indeed, in some contexts determination of "medical utility" may be required by the principle of fairness. It may be "unfortunate" when one patient receives an organ over another because of "medical utility," but it is not necessarily "unfair." Appeals to "medical utility" in the distribution of organs do not necessarily violate the principle of equal concern and respect; judgments based on "medical utility" do not necessarily show disrespect and contempt, which, by contrast, are inevitable in judgments based on patients' comparative "social utility." Furthermore, acceptance of "medical utility" does not commit one to utilitarianism as a foundational or substantive moral doctrine; "medical utility" can (and should) be accepted in any defensible deontological framework as well. Holding that a lexical or serial order of these criteria is impossible also does not entail utilitarianism. In addition, using a Rawlsian contract metaphor, we can argue that in a fair set of decision-making circumstances behind the veil of ignorance, patients not knowing their own medical conditions would choose criteria of "medical utility." Such a hypothetical contract allegedly makes the distribution fair to potential recipients. Finally, others also argue that fairness to donors requires that organs be used effectively and efficiently.

Judgments about medical need and probability of success, as already noted, are value-laden. Consider, for example, the debates about what will count as *success*—such as length of graft survival, length of patient survival, quality of life, rehabilitation—and about which factors influence the *probability of success*. Some contraindications are well established, such as mismatched blood group or positive donor-recipient crossmatch. Over time the UNOS point system for kidneys has stressed, to varying degrees, tissue matching on medical utility grounds. It is also not unfair to use tissue matching, not only because of medical utility, but because tissue matching functions as a kind of natural lottery, which involves the randomness of the HLA match between available donors and recipients. However, there is vigorous debate about the relative importance of tissue matching now that cyclosporine and other immunosuppressive medications are available, and this technical debate influences judgments about the conditions under which kidneys should be shared outside the location where they are retrieved. For example, since cyclosporine is nephrotoxic, a retrieved kidney needs to be transplanted sooner than usual in order to increase the chances of successful transplantation when that immunosuppressive medication is used. Furthermore, studies also indicate that the length of cold ischemic time prior to the kidney's transplantation has an impact on graft survival.

Tissue matching needs ongoing scrutiny. First, in view of the scientific controversy, it is essential to see if certain levels of tissue match or mismatch really make significant differences in the outcome of transplantation over time. Second, it is morally imperative to monitor the operation of the point systems to make sure that tissue matching does not have unjustified discriminatory effects, for example, against blacks and other minorities. As noted, discrimination may already occur against blacks and other minorities in admission to waiting lists, and tissue matching may have discriminatory effects for some patients on the waiting list. For example, most organ donors are white, certain HLA phenotypes are different in white, black, and Hispanic populations, the identification of HLA phenotypes is less complete for blacks and Hispanics, nonwhites have a higher rate of end-stage renal disease, and nonwhite populations are

disproportionately represented on dialysis lists. In this context, Robert Veatch argues that "if organs are to be allocated on the basis of degree of tissue match, the policy is, *de facto*, a whites-first policy."⁹ Monitoring the operation of each point system will provide evidence regarding discriminatory effects. If such discriminatory effects emerge, then it may be necessary to sacrifice some probability of success in order to take affirmative action to protect blacks and other minorities. Indeed, such considerations figured significantly in the UNOS decision to alter, in 1995, the point system for the allocation of cadaveric kidneys to eliminate points given from some levels of match and to increase the role of time on the waiting lists.

Sometimes there is a tension between urgency of need and probability of success. Robert M. Veatch contends that "a justice-based allocation . . . would demand that highest priority be given to medical need and length of time the patient has been in need."¹⁰ Apparently some potential recipients would choose such criteria. For example, in determining who will receive a heart, members of a Canadian transplant team note, "it becomes a difficult ethical issue as to whether the patient with the better outcome or the individual with the greatest urgency should receive the heart. The patients themselves would opt for the patient with the greatest urgency and by and large that is the decision taken by the team. However, one is conscious of the fact that one may be affecting the overall success rate by making choices in favor of individual patient urgency rather than making them on the basis of success."

Tensions between medical urgency and probability of success may vary greatly depending on the organ in question. For instance, there is debate in heart transplantation about the use of artificial hearts and other assist devices, in part because they have sometimes given patients priority for scarce donor hearts on the basis of medical need, even though their chances for success may have been minimal. Critics such as George Annas charge that using the total artificial heart as a temporary bridge to transplantation does not save lives; it only changes the identities of those receiving heart transplants by giving very sick patients priority.¹¹ And UNOS revised its criteria for the allocation of hearts so that patients on mechanical assist devices would no longer receive priority

over all other candidates in their area; under the revised allocation system, patients who require inotropic agents and are in intensive care units would also appear in the top priority group. One goal of this revision was to remove any incentive for a physician to put a patient on an assist device in order to improve his or her chances of getting a heart transplant.

In liver transplantation, to take another example, the dominant practice has been to give the sickest patient the highest priority, but "medical utility" (and some would include cost-effectiveness) would often dictate placing the liver in the fittest patient and realizing the greatest medical benefit (at the lowest cost). Another reason for priority to those with a higher probability of benefit is that "as time goes on . . . the fitter patients become increasingly ill, their survivability on the waiting list declines, and their operative risk soars." Nevertheless, as Olga Jonasson notes, there is clearly one case in which the sickest of all patients awaiting liver transplants is also the best candidate for successful transplantation—the young, previously healthy patient with fulminant acute liver failure.

The category of medical urgency may not be as important when an artificial organ can be used as a backup (for example, dialysis for end-stage renal failure). However, some argue that medical urgency should include not only the immediate threat of death but also the likelihood of not receiving another organ because of presensitization particularly because sensitized patients now constitute a hard core of the waiting lists for kidney transplants. The Task Force recommended that a highly sensitized patient who is predicted on the basis of either a computer antibody analysis or an actual crossmatch to accept the transplant should be given priority over equivalently matched nonsensitized patients. And yet the success rates may be lower for sensitized patients than for nonsensitized patients.

Another problem is that medical urgency is a manipulable category. It is reportedly abused at times by physicians eager to protect their patients by declaring them medically urgent in order to increase their chances for a transplant. These reports are not implausible in light of studies indicating that physicians are willing to lie in order to promote their patients' welfare in the health care system, such as using a misleading category in

order to enable the patient to have a diagnostic procedure covered by health insurance.

In short, it is not at all clear that a general, a priori formulation of the appropriate relation between medical need and probability of success within medical utility is defensible, in part because of the variations in organ systems. Thus, the proposals may have to be organ specific, and variations can be expected in policies from one organ to another. Ongoing monitoring and assessment of current policies, with public input and with special attention to the proper use of the category of medical urgency, appears to be the most appropriate action. As the federal Task Force recommended,

A decision on how to apply the criterion of urgency must be developed by a thoughtful and broadly representative group, which must struggle with the concept of [the] best use of organs in the context of compassion and humanitarianism. Because donated organs are a scarce resource, policies to resolve conflicts between equity and efficiency that arise in the distribution of organs should be determined by a broadly representative group that includes patient, community and ethical perspectives, as well as those of the medical professionals involved.¹²

TIME ON THE WAITING LIST

Many including this writer have argued that randomization or time on the waiting list is a fair way to allocate scarce lifesaving resources under some circumstances. I developed my argument to this effect in 1970 when the debate was mainly about kidney dialysis.¹³ . . . At that time I argued that once the pool of medically eligible candidates has been determined, it is then fair to make the final selection by randomization or queuing. However, I believe that matters are somewhat different when the scarce medical resource is an organ, which cannot be reused. Now I would argue that medical utility should also be used to determine which candidate should receive the organ, after the eligible candidates have been identified on grounds of medical utility. A major reason is not wasting the gift of life; the organ has been donated for effective use. Giving an organ to a patient who has a very limited chance of success, perhaps because of poor tissue match, increases the probability that he or she will then need another transplant for survival,

further reducing the chances for others as well as for his or her own successful transplantation.

Nevertheless, it is important to reject positions that rule out queuing or time on the waiting list as morally irrelevant or even morally pernicious. For example, Olga Jonasson argues that "length of time on the waiting list is the least fair, most easily manipulated, and most mindless of all methods of organ allocation," and Ruth Macklin argues that the principle of "first come, first served" is inapplicable and even inequitable in the allocation of scarce medical resources because it ignores different medical needs and prognoses.

By contrast to those positions, if two or more patients are equally good candidates for a particular organ according to the medical criteria of need and probability of success, their time on the waiting list may be the fairest way to make the final selection. This approach is similar to that recommended by the federal Task Force.¹⁴ The original UNOS point system for kidneys gave more weight to time on the waiting list and also to sensitization, but since highly sensitized patients are likely to spend more time on the waiting list they were, in effect, counted twice. Some argued that such double counting is justifiable because of their difficulty of obtaining organs, while others noted that such patients might then receive priority over much better matched patients. In the revised point system in 1989, time on the waiting list functioned more as a tiebreaker in the allocation of kidneys in the UNOS point system, while in the revised point system in 1995, it again received greater weight (the point value was raised from 0.5 to one point for each full year of waiting time).

Queuing is often favored because it appears to be objective and impersonal, but the justification of its use in patient selection depends on certain values (or principles), such as fair opportunity. And there are both ethical and practical problems. It is not always easy to determine when a patient entered the waiting list; one way is the accession time on the UNOS list. But, as Jonasson notes, it is easy to manipulate this criterion, for example, by putting patients on the list before they become dialysis dependent. In addition, it is important to note that the fairness of queuing (as well as of randomization) depends in part on background conditions. For example, some people may not seek care early because of limited financial resources

and insurance; others may receive inadequate medical advice about how early to seek transplantation; and so forth.

There are clear differences in orientation between two approaches to time on the waiting list—use time on the waiting list unless there are substantial differences in medical utility, or follow medical utility unless there are no substantial differences and then use time on the waiting list. However, they should, practically speaking, end up at the same place, *if* there is a consensus on what constitutes “substantial differences in medical utility. . . .

THE ACCESS OF FOREIGN NATIONALS TO ORGANS DONATED IN THE UNITED STATES

Another major question arises from the Task Force’s recommendation that “donated organs be considered a national resource”: Should foreign nationals have access to organs donated in the United States? The issue of geographical boundaries, or “accidents of geography,” is international as well as intranational. Of the approximately 6,000 cadaveric kidneys transplanted in the United States in 1985, 300 went to nonresident aliens who had come to the United States for medical care, and 200 to 250 additional kidneys were shipped abroad for use in other countries.

The debate about transplanting organs obtained in the United States into foreign nationals and about exporting those organs invokes various moral principles as well as diverse convictions about the ownership of donated organs. Some who propose physician discretion in the selection of patients insist that the ideal of medical humanitarianism precludes the use of criteria such as national residence. By contrast, critics of physician discretion contend that the distribution of donated organs is not merely or even primarily a matter of medical humanitarianism but of social humanitarianism. I agree that donated organs belong to the community, that procurement and transplantation teams only serve as trustees and stewards of donated organs, and that the debate essentially concerns social rather than medical humanitarianism.

It should not be surprising that the most vigorous and divisive debate on the federal Task Force

centered on the access of foreign nationals to cadaveric organs donated in the United States. Members of the Task Force sought to balance principles of fairness, beneficence (expressed as compassion and generosity), and utility and efficiency, particularly in the avoidance of kidney wastage. There was little or no interest in excluding foreign nationals altogether, for instance, when organs would otherwise go to waste. Rather, the debate focused on whether to adopt (1) a policy of U.S. citizens and residents first—sometimes called “Americans first”—which would allow some nonresident aliens on waiting lists but would not allow them to receive any particular donated organ unless no U.S. citizen or resident could benefit from it, or (2) a policy that would set a ceiling on the number of nonresident aliens on the waiting list, but would accord equal treatment to everyone on the list, regardless of national residence. The Task Force recommended the first policy for hearts and livers and the second policy for kidneys, recommending a ceiling of 10 percent until the matter could be reviewed by the OPTN (which became UNOS).

The majority of the Task Force distinguished between these two policies on the grounds that kidneys are not as scarce as extrarenal organs, and dialysis is usually available and feasible as a backup or an alternative to transplantation in the treatment of end-stage renal failure. However, eight of the twenty-five members of the Task Force dissented from the recommendation for renal organs. These dissenters argued that it is unfair to members of the national community to deny or to delay their access to organs donated in the United States and unfair to use taxpayers’ money to obtain kidneys that would be distributed to nonresident aliens. . . .

After reviewing various arguments, UNOS adopted a policy that established some limits and directions but relied mainly on a procedure of accountability in the transplantation of nonresident aliens. It required UNOS members to charge the same fees for nonresident aliens as for domestic patients, to treat all patients accepted on transplant waiting lists according to UNOS policies for the equitable distribution of donated organs, and to arrange any exportation of organs through UNOS and then only after no suitable recipient could be located in the United States or Canada

(included because of sharing arrangements). Accountability was established in several ways. On the local level, centers that accept nonresident aliens on their waiting lists should establish a mechanism for community participation and review. On the national level, the UNOS committee on foreign relations has a right to audit all transplant center activities relating to nonresident aliens and will automatically review any center that has more than 10 percent of its transplant recipients from foreign nationals.

ABILITY TO PAY

So far I have examined issues of patient selection for organs for transplantation—both formation of the waiting list and selection to receive a particular organ—apart from questions of costs. Yet organ transplants are notoriously very expensive. Our society has responded very differently to different organ transplant procedures. Through Medicare's End-Stage Renal Disease (ESRD) program, virtually everyone who needs a kidney transplant (or dialysis) is covered, while coverage for heart and liver transplantation is at best spotty. Should ability to pay function as a criterion for admission to waiting lists? Should there be a "green screen" for access to waiting lists for organ transplantation? These questions cannot be directly addressed by UNOS; they emerge on other levels for other social institutions, particularly for the federal and state governments.

As part of its efforts to propose policies to ensure equitable access to organ transplantation, the federal Task Force on Organ Transplantation offered several arguments in favor of increasing societal funding for organ transplants—on the one hand, for immunosuppressive medications for organ transplants already funded (mainly kidneys), and, on the other hand, for extrarenal organ transplants not currently funded.

The Task Force concluded that coverage for immunosuppressive medications was important because, for example, wealth discrimination had reentered the ESRD program, which had been designed to eliminate distribution of artificial and transplanted kidneys according to ability to pay. Noting that approximately 25 percent of the transplant population (for all organs) lacked state or

private coverage for immunosuppressive medications, especially cyclosporine, which was then estimated to cost approximately \$5,000 to \$7,000 a year, the Task Force "found evidence that inability to pay for immunosuppressive medications had been a factor in the initial selection of patients for transplantation" and that some transplant recipients had undergone nonmedically indicated—and potentially risky—changes in their medications because of the costs. The Medicare coverage that was subsequently approved, in part in response to the Task Force report, was limited to one year after the transplant. Further study is needed to determine the extent to which limited coverage of immunosuppressive medications limits access to transplants. (The coverage is now being gradually extended to a full three-year period.)

Much of the Task Force's concern about fair access focused on extrarenal organs—hearts and livers—in view of the limited and uneven provision of funds for them. And, according to the Task Force, there are several arguments for a societal obligation, to be discharged by the federal government as a last resort, to provide funds for extrarenal transplants in order to ensure fair access. One argument focuses on the *continuity* between extrarenal organ transplants and other medical procedures that are already covered, such as kidney transplants and dialysis. Appealing to the principle of consistency or universalizability, this argument accepts the precedent value of prior and current policy decisions. Still another premise in the argument is empirical—extrarenal transplants are comparable in efficacy and costs to procedures that are routinely covered. In response to worries about cost containment, defenders of public funding for organ transplantation hold that it is unfair to impose the major burden of cost containment on patients with end-stage organ failure who need transplants. The burdens of cost containment should themselves be distributed equitably across categories of patients needing health care.

A second argument focuses on the *distinctiveness* or *uniqueness* of organ transplantation, particularly the social practices of procurement that provide the organs for transplantation. This argument identifies an important moral connection between organ procurement, including organ donation, and organ distribution and allocation. In its efforts to increase the supply of organs, our society

requests donations of organs from people of all socioeconomic classes—for example, through presidential appeals for organ donations or through state “required request” and “routine inquiry” statutes, which mandate that institutions inquire about an individual’s or family’s willingness to donate, or even request such a donation. However, it is unfair and even exploitative for society to ask people, rich and poor alike, to donate organs if access to donated organs will be determined by ability to pay rather than by medical need, probability of success, and time on the waiting list.¹⁵

A third and related argument builds on societal opposition to commercialization and commodification of human body parts, as expressed in various laws and policies. . . . Federal legislation—as well as legislation in some states—prohibits individuals from transferring organs over which they have dispositional authority for valuable consideration.¹⁶ In addition, various professional organizations involved in organ transplantation have taken a stand against the sale of organs for transplantation. It is difficult, according to this third argument, to distinguish (1) buying an organ for transplantation and then hiring a surgeon to perform the procedure from (2) purchasing an organ transplantation procedure that includes a (donated) organ as well as the surgeon’s (and others’) services.

These last two principled arguments may be combined with consequentialist arguments. There are legitimate worries about the impact of unequal access to organ transplants, based on inability to pay, on the system of organ procurement that includes gifts of organs from individuals and their families. As I noted earlier, there is substantial evidence that attitudes of distrust limit organ donation; this distrust appears to be directed at both organ procurement (e.g., the fear the potential donors will be declared dead prematurely) and organ distribution (e.g., the concern that potential transplant recipients from higher socioeconomic classes will receive priority). Thus, it is not at all surprising that after Oregon decided to stop providing Medicaid funds for most organ transplants, “a boycott of organ donations was organized by some low-income people.” And cynical comments about how rapidly famous people, such as Mickey Mantle, receive scarce organ transplants reflect public suspicion of organ allocation policies.

A final argument is closely related to the first one, but instead of building on what the society has already decided to do regarding other health care, it focuses on the federal government’s obligation, at least as a last resort, to ensure fair access to health care, including organ transplantation, by removing financial barriers, if necessary. For example, this argument might appeal to what the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research construed as society’s obligation to provide equitable access to an adequate level of health care without excessive burdens.* (Even though this argument may appear to be independent of social practices, it may—and should—nevertheless appeal to principles and values embedded in those practices.) Whatever the foundation of the obligation, there will still be vigorous debate about what counts as an adequate level of health care and whether organ transplants qualify. And this debate moves us to questions of *macroallocation*. It is now standard to distinguish microallocation from macroallocation. For example, Engelhardt uses the term “macroallocation” to refer to “allocations among general categories of expenditures,” and the term “microallocation” to refer to “choices among particular individuals as to whether they will be recipients of resources and in what amount.”¹⁷

The question of microallocation is *who* will receive a particular scarce good; the questions of macroallocation focus on *how much* of a good will be made available, where financial resources can alter the availability of that good, such as organ transplants or AZT for AIDS patients. It is important to note that while macroallocation and microallocation are analytically distinct, they are significantly related. Obviously macroallocation decisions determine the extent of scarcity and the difficulty of patient selection by in part determining how much of a good will be made available in a society. If a particular technology or mode of health care is in limited supply, as is often the case, then there may be difficult microallocation decisions about who will receive this particular scarce good. But problems in microallocation may also have an impact on macroallocation decisions. For instance, it has been argued that the federal

*EDITORS’ NOTE: See Part Six, Section One.

government decided to provide virtually universal funding for treatments for end-stage renal disease in part to eliminate the problem of patient selection for kidney dialysis and transplantation, that is, the problem of having health care professionals and committees explicitly determine who would live and who would die. . . .

CONCLUSION

In conclusion, I want to draw together several points and mention a few others that grow out of this analysis and properly set the context for discussion of a political-legal right to health care. First, I have stressed the principle of fairness (equity or justice). This principle is not easy to specify or to apply, for there are vigorous disputes about its meaning (e.g., whether it excludes medical utility) and about its weight (e.g., when it comes into conflict with other principles).

Second, fairness is not the only principle; there are others, including utility and respect for personal autonomy. Fairness does not always oppose such principles as medical utility, as I argued in my proposals for a fair use of medical utility (medical need and probability of success) in the allocation and distribution of organs for transplantation. Even when there are conflicts it is not possible to indicate in advance exactly which principle should have priority. Seeking to balance these various principles is a worthy process and goal, but sometimes trade-offs are inevitable in policies of allocation and distribution.¹⁸

Third, if we ask about the fairness of providing or not providing funds for extrarenal transplants, it may be difficult to answer that question in an unfair system. If, as Norman Daniels argues, "our system is, in general, unjust,"¹⁹ then it may be difficult to determine whether it would be just or unjust to press for and obtain funds for organ transplants or AZT or some other treatment. Which policy of allocation would be more likely to lead to a more just system? And, if neither would, which should be adopted as the morally preferable—perhaps because more just—policy within an unjust system? I will provide a context for such judgments in the next chapter, when I consider a general political-legal right to health care, which is currently missing from U.S. health policy.

Fourth, not only do our reflections about policies of allocation and distribution occur within a particular sociopolitical context, but that context itself often changes over time. Thus, it may be appropriate to develop policies to reaffirm some principles or values that have been neglected, or even overridden, in order to maintain their significance for the society over time.²⁰ There is no reason to suppose that within the range of ethically acceptable policies only one should be implemented over time.

Finally, ethical theories, including theories of justice and fairness, may have only limited applicability, partly in view of conditions that limit their feasibility. The phrase "applied ethics"—the application of ethical principles, rules, and theories—is not the most appropriate, for the task for ethics is more that of illuminating the ethical presuppositions and implications of the choices we have to make in the real world, in response to such questions as how organs should be distributed and allocated and whether organ transplants should receive societal funds. Those questions arise in a complex mix of social, political, scientific, medical, and other factors. "Illumination" rather than "resolution" is the main contribution of ethical theory, and it properly takes the form of "practical ethics" rather than "applied ethics."

NOTES

1. Jeffrey M Protas, "Nonresident Aliens and Access to Organ Transplant," *Transplantation Proceedings* 21 (June 1989) 3428.
2. For a discussion of criteria of justice, see Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th ed. (New York: Oxford University Press, 1994), chap. 6.
3. For the distinction between "medical utility" and "social utility," see James F. Childress, "Triage in Neonatal Intensive Care: The Limitations of a Metaphor," *Virginia Law Review* 69 (April 1983): 547-61.
4. See P. W. Eggers, "Effect of Transplantation on the Medicare End Stage Renal Disease Program," *New England Journal of Medicine* 318 (1989): 223-29.
5. See T. E. Starzl, T. R. Hakala, A. Tzakis et al., "A Multifactorial System for Equitable Selection of Cadaver Kidney Recipients," *Journal of the American Medical Association* 257 (1987): 3073-75.
6. UNOS, *Final Statement of Policy: UNOS Policy Regarding Utilization of the Point System for Cadaveric Kidney Allocation* (Richmond, VA: UNOS, April 4, 1989), which

gives the history of the policy development to that point, as well as an overview of the different stages and arguments involved in the policy formation.

7. T. E. Starzl, R. Shaprio, and L. Teperman, "The Point System for Organ Distribution," *Transplantation Proceedings* 21 (June 1989): 3434.
8. Daniel Wilder, "Equity, Efficacy, and the Point System for Transplant Recipient Selection," *Transplantation Proceedings* 21 (June 1989): 3437.
9. Robert M. Veatch, "Allocating Organs by Utilitarianism Is Seen as Favoring Whites over Blacks," *Kennedy Institute of Ethics Newsletter* 3 (July 1989):1 and 3.
10. Robert M. Veatch, *Death, Dying and the Biological Revolution*, rev ed. (New Haven: Yale University Press, 1989), p. 210.
11. George J. Annas, "No Cheers for Temporary Artificial Hearts," *Hastings Center Report* 15 (October 1985).
12. Task Force, *Organ Transplantation*, pp. 88-89.
13. James F. Childress, "Who Shall Live When Not All Can Live?" *Soundings* 53 (1970): 339-55.
14. See Task Force, *Organ Transplantation*, chap. 5.
15. Contrast Norman Daniels, "Comment: Ability to Pay and Access to Transplantation," *Transplantation Proceedings* 21 (June 1989): 3434. For a sharp criticism see F. M. Kamm, "The Report of the U.S. Task Force on

Organ Transplantation: Criticisms and Alternatives," *Mount Sinai Journal of Medicine* 56 (May 1989): 207-20.

16. See PL 98-507.
17. H. Tristram Engelhardt, Jr., *Foundations of Bioethics* (New York: Oxford University Press, 1986), p. 369, n. 7.
18. For a sketch of a model of balancing, which is, however, not fully consistent, see "The UNOS Statement of Principles and Objectives of Equitable Organ Allocation," *LNOS Update* (August 1994), pp. 20-38. For a strong argument against balancing medical utility against justice, with justice interpreted as requiring "opportunities for equality of health," see Robert M. Veatch's response to an earlier version of this chapter.* My reasons for rejecting much of Veatch's position appear in the argument for medical utility in the previous chapter as well as in the overall argument of this chapter, even though I do not directly address his arguments.
19. Norman Daniels, *Just Health Care* (Cambridge: Cambridge University Press, 1985), which has greatly influenced these concluding remarks.
20. Guido Calabresi and Philip Bobbitt, *Tragic Choices* (New York: Norton, 1977).

*EDITORS' NOTE: See this section.

Equality, Justice, and Rightness in Allocating Health Care: A Response to James Childress

Robert M. Veatch

James Childress has given us a carefully reasoned and generally plausible account of an ethics of allocating resources and its implications for organ transplantation, one that reflects a moral theory far more subtle than a simple strategy of maximizing good consequences from the scarce health care resources we have available. He shows that the decisions made about ethical theory make a difference in how people will get treated by the health care system. Rather modest changes in the theory, however, can have important implications for

decisions such as who should get scarce organs for transplantation.

I would like to suggest some places where some of these small changes in the general theory would be plausible and then comment on how that has forced me in my role as a member of the Washington Regional Transplant consortium to vote for a different kidney allocation formula.

Childress and I agree that justice or fairness is one among several right-making principles for moral action. This implies that it is theoretically possible that, depending on one's formula for resolving conflict among ethical principles, a policy that is just or fair may turn out not to be exactly the policy that is ethically right, all things considered. Before tackling the question of the correct formula for resolving

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