

# Public Health and the Law

## The Prostitute, the Playboy, and the Poet: Rationing Schemes for Organ Transplantation

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In the public debate about the availability of heart and liver transplants, the issue of rationing on a massive scale has been credibly raised for the first time in United States medical care. In an era of scarce resources, the eventual arrival of such a discussion was, of course, inevitable.<sup>1</sup> Unless we decide to ban heart and liver transplantation, or make them available to everyone, some rationing scheme must be used to choose among potential transplant candidates. The debate has existed throughout the history of medical ethics. Traditionally it has been stated as a choice between saving one of two patients, both of whom require the immediate assistance of the only available physician to survive.

National attention was focused on decisions regarding the rationing of kidney dialysis machines when they were first used on a limited basis in the late 1960s. As one commentator described the debate within the medical profession:

"Shall machines or organs go to the sickest, or to the ones with most promise of recovery; on a first-come, first-served basis; to the most 'valuable' patient (based on wealth, education, position, what?); to the one with the most dependents; to women and children first; to those who can pay; to whom? Or should lots be cast, impersonally and uncritically?"<sup>2</sup>

In Seattle, Washington, an anonymous screening committee was set up to pick who among competing candidates would receive the life-saving technology. One lay member of the screening committee is quoted as saying:

"The choices were hard . . . I remember voting against a young woman who was a known prostitute. I found I couldn't vote for her, rather than another candidate, a young wife and mother. I also voted against a young man who, until he learned he had renal failure, had been a ne'er do-well, a real playboy. He promised he would reform his character, go back to school, and so on, if only he were selected for treatment. But I felt I'd lived long enough to know that a person like that won't really do what he was promising at the time."<sup>3</sup>

When the biases and selection criteria of the committee were made public, there was a general negative reaction against this type of arbitrary device. Two experts reacted to the "numbing accounts of how close to the surface lie the

prejudices and mindless clichés that pollute the committee's deliberations," by concluding that the committee was "measuring persons in accordance with its own middle-class values." The committee process, they noted, ruled out "creative nonconformists" and made the Pacific Northwest "no place for a Henry David Thoreau with bad kidneys."<sup>4</sup>

To avoid having to make such explicit, arbitrary, "social worth" determinations, the Congress, in 1972, enacted legislation that provided federal funds for virtually all kidney dialysis and kidney transplantation procedures in the United States.<sup>5</sup> This decision, however, simply served to postpone the time when identical decisions will have to be made about candidates for heart and liver transplantation in a society that does not provide sufficient financial and medical resources to provide all "suitable" candidates with the operation.

There are four major approaches to rationing scarce medical resources: the market approach; the selection committee approach; the lottery approach; and the "customary" approach.<sup>1</sup>

### *The Market Approach*

The market approach would provide an organ to everyone who could pay for it with their own funds or private insurance. It puts a very high value on individual rights, and a very low value on equality and fairness. It has properly been criticized on a number of bases, including that the transplant technologies have been developed and are supported with public funds, that medical resources used for transplantation will not be available for higher priority care, and that financial success alone is an insufficient justification for demanding a medical procedure. Most telling is its complete lack of concern for fairness and equity.<sup>6</sup>

A "bake sale" or charity approach that requires the less financially fortunate to make public appeals for funding is demeaning to the individuals involved, and to society as a whole. Rationing by financial ability says we do not believe in equality, but believe that a price can and should be placed on human life and that it should be paid by the individual whose life is at stake. Neither belief is tolerable in a society in which income is inequitably distributed.

### *The Committee Selection Process*

The Seattle Selection Committee is a model of the committee process. Ethics Committees set up in some hospitals to decide whether or not certain handicapped newborn infants should be given medical care may represent another.<sup>7</sup> These committees have developed because it was

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seen as unworkable or unwise to explicitly set forth the criteria on which selection decisions would be made. But only two results are possible, as Professor Guido Calabresi has pointed out: either a pattern of decision-making will develop or it will not. If a pattern does develop (e.g., in Seattle, the imposition of middle-class values), then it can be articulated and those decision "rules" codified and used directly, without resort to the committee. If a pattern does not develop, the committee is vulnerable to the charge that it is acting arbitrarily, or dishonestly, and therefore cannot be permitted to continue to make such important decisions.<sup>1</sup>

In the end, public designation of a committee to make selection decisions on vague criteria will fail because it too closely involves the state and all members of society in explicitly preferring specific individuals over others, and in devaluing the interests those others have in living. It thus directly undermines, as surely as the market system does, society's view of equality and the value of human life.

### *The Lottery Approach*

The lottery approach is the ultimate equalizer which puts equality ahead of every other value. This makes it extremely attractive, since all comers have an equal chance at selection regardless of race, color, creed, or financial status. On the other hand, it offends our notions of efficiency and fairness since it makes *no* distinctions among such things as the strength of the desires of the candidates, their potential survival, and their quality of life. In this sense it is a mindless method of trying to solve society's dilemma which is caused by its unwillingness or inability to spend enough resources to make a lottery unnecessary. By making this macro spending decision evident to all, it also undermines society's view of the pricelessness of human life. A first-come, first-served system is a type of natural lottery since referral to a transplant program is generally random in time. Nonetheless, higher income groups have quicker access to referral networks and thus have an inherent advantage over the poor in a strict first-come, first-served system.<sup>8,9</sup>

### *The Customary Approach*

Society has traditionally attempted to avoid explicitly recognizing that we are making a choice not to save individual lives because it is too expensive to do so. As long as such decisions are not explicitly acknowledged, they can be tolerated by society. For example, until recently there was said to be a general understanding among general practitioners in Britain that individuals over age 55 suffering from end-stage kidney disease not be referred for dialysis or transplant. In 1984, however, this unwritten practice became highly publicized, with figures that showed a rate of new cases of end-stage kidney disease treated in Britain at 40 per million (versus the US figure of 80 per million) resulting in 1500–3000 "unnecessary deaths" annually.<sup>10</sup> This has, predictably, led to movements to enlarge the National Health Service budget to expand dialysis services to meet this need, a more socially acceptable solution than permitting the now publicly recognized situation to continue.

In the US, the customary approach permits individual physicians to select their patients on the basis of medical criteria or clinical suitability. This, however, contains much hidden social worth criteria. For example, one criterion, common in the transplant literature, requires an individual to have sufficient family support for successful aftercare. This discriminates against individuals without families and those

who have become alienated from their families. The criterion may be relevant, but it is hardly medical.

Similar observations can be made about medical criteria that include IQ, mental illness, criminal records, employment, indigency, alcoholism, drug addiction, or geographical location. Age is perhaps more difficult, since it may be impressionistically related to outcome. But it is not medically logical to assume that an individual who is 49 years old is necessarily a better medical candidate for a transplant than one who is 50 years old. Unless specific examination of the characteristics of older persons that make them less desirable candidates is undertaken, such a cut off is arbitrary, and thus devalues the lives of older citizens. The same can be said of blanket exclusions of alcoholics and drug addicts.

In short, the customary approach has one great advantage for society and one great disadvantage: it gives us the illusion that we do not have to make choices; but the cost is mass deception, and when this deception is uncovered, we must deal with it either by universal entitlement or by choosing another method of patient selection.

### *A Combination of Approaches*

A socially acceptable approach must be fair, efficient, and reflective of important social values. The most important values at stake in organ transplantation are fairness itself, equity in the sense of equality, and the value of life. To promote efficiency, it is important that no one receive a transplant unless they want one and are likely to obtain significant benefit from it in the sense of years of life at a reasonable level of functioning.

Accordingly, it is appropriate for there to be an initial screening process that is based *exclusively* on medical criteria designed to measure the probability of a successful transplant, i.e., one in which the patient survives for at least a number of years and is rehabilitated. There is room in medical criteria for social worth judgments, but there is probably no way to avoid this completely. For example, it has been noted that "in many respects social and medical criteria are inextricably intertwined" and that therefore medical criteria might "exclude the poor and disadvantaged because health and socioeconomic status are highly interdependent."<sup>11</sup> Roger Evans gives an example. In the End Stage Renal Disease Program, "those of lower socioeconomic status are likely to have multiple comorbid health conditions such as diabetes, hepatitis, and hypertension" making them both less desirable candidates and more expensive to treat.<sup>11</sup>

To prevent the gulf between the haves and have nots from widening, we must make every reasonable attempt to develop medical criteria that are objective and independent of social worth categories. One minimal way to approach this is to require that medical screening be reviewed and approved by an ethics committee with significant public representation, filed with a public agency, and made readily available to the public for comment. In the event that more than one hospital in a state or region is offering a particular transplant service, it would be most fair and efficient for the individual hospitals to perform the initial medical screening themselves (based on the uniform, objective criteria), but to have all subsequent non-medical selection done by a method approved by a single selection committee composed of representatives of all hospitals engaged in the particular transplant procedure, as well as significant representation of the public at large.

As this implies, after the medical screening is performed, there may be more acceptable candidates in the "pool" than there are organs or surgical teams to go around. Selection among waiting candidates will then be necessary. This situation occurs now in kidney transplantation, but since the organ matching is much more sophisticated than in hearts and livers (permitting much more precise matching of organ and recipient), and since dialysis permits individuals to wait almost indefinitely for an organ without risking death, the situations are not close enough to permit use of the same matching criteria. On the other hand, to the extent that organs are specifically tissue- and size-matched and fairly distributed to the best matched candidate, the organ distribution system itself will resemble a natural lottery.

When a pool of acceptable candidates is developed, a decision about who gets the next available, suitable organ must be made. We must choose between using a conscious, value-laden, social worth selection criterion (including a committee to make the actual choice), or some type of random device. In view of the unacceptability and arbitrariness of social worth criteria being applied, implicitly or explicitly, by committee, this method is neither viable nor proper. On the other hand, strict adherence to a lottery might create a situation where an individual who has only a one-in-four chance of living five years with a transplant (but who could survive another six months without one) would get an organ before an individual who could survive as long or longer, but who will die within days or hours if he or she is not immediately transplanted. Accordingly, the most reasonable approach seems to be to allocate organs on a first-come, first-served basis to members of the pool but permit individuals to "jump" the queue if the second level selection committee believes they are in immediate danger of death (but still have a reasonable prospect for long-term survival with a transplant) and the person who would otherwise get the organ can survive long enough to be reasonably assured that he or she will be able to get another organ.

The first-come, first-served method of basic selection (after a medical screen) seems the preferred method because it most closely approximates the randomness of a straight lottery without the obviousness of making equity the only promoted value. Some unfairness is introduced by the fact that the more wealthy and medically astute will likely get into the pool first, and thus be ahead in line, but this advantage should decrease sharply as public awareness of the system grows. The possibility of unfairness is also inherent in permitting individuals to jump the queue, but some flexibility needs to be retained in the system to permit it to respond to reasonable contingencies.

We will have to face the fact that should the resources devoted to organ transplantation be limited (as they are now and are likely to be in the future), at some point it is likely that significant numbers of individuals will die in the pool waiting for a transplant. Three things can be done to avoid this: 1) medical criteria can be made stricter, perhaps by adding a more rigorous notion of "quality" of life to longevity and prospects for rehabilitation; 2) resources devoted to

transplantation and organ procurement can be increased; or 3) individuals can be persuaded not to attempt to join the pool.

Of these three options, only the third has the promise of both conserving resources and promoting autonomy. While most persons medically eligible for a transplant would probably want one, some would not—at least if they understood all that was involved, including the need for a lifetime commitment to daily immunosuppression medications, and periodic medical monitoring for rejection symptoms. Accordingly, it makes public policy sense to publicize the risks and side effects of transplantation, and to require careful explanations of the procedure be given to prospective patients *before* they undergo medical screening. It is likely that by the time patients come to the transplant center they have made up their minds and would do almost anything to get the transplant. Nonetheless, if there are patients who, when confronted with all the facts, would voluntarily elect not to proceed, we enhance both their own freedom and the efficiency and cost-effectiveness of the transplantation system by screening them out as early as possible.

### Conclusion

Choices among patients that seem to condemn some to death and give others an opportunity to survive will always be tragic. Society has developed a number of mechanisms to make such decisions more acceptable by camouflaging them. In an era of scarce resources and conscious cost containment, such mechanisms will become public, and they will be usable only if they are fair and efficient. If they are not so perceived, we will shift from one mechanism to another in an effort to continue the illusion that tragic choices really don't have to be made, and that we can simultaneously move toward equity of access, quality of services, and cost containment without any challenges to our values. Along with the prostitute, the playboy, and the poet, we all need to be involved in the development of an access model to extreme and expensive medical technologies with which we can live.

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