

# Virtual Mentor

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## Policy forum

### **Beyond scarcity: poverty as a contraindication for organ transplantation**

by Mary Simmerling, PhD

In almost every aspect of society, the resource-rich have an advantage over the resource-poor. The richer people are, the longer and healthier are their lives [1, 2]. The philosopher Norman Daniels has argued that social policies are responsible for the inequalities that produce health disparities and suggests that we must look upstream from the point of medical delivery when examining the fairness of the distribution of these goods. Daniels uses Rawls' theory of justice as fairness [3] as the basis for his argument that health care is morally unique because it protects an individual's equality of opportunity:

The central moral importance, for purposes of justice, of preventing and treating disease and disability with effective health care services...derives from the way in which protecting normal functioning contributes to protecting opportunity...by keeping people close to normal functioning, health care preserves for people the ability to participate in the political, social and economic life of their society [1].

That is, by keeping people close to normal functioning, medicine also aims at the goal of protecting their equality of opportunity. In this policy forum, I will consider the extent to which medicine has met this goal in the area of organ transplantation.

Daniels claims that a principle that assures fair equality of opportunity will—among other things—prohibit discriminatory barriers to accessing the goods of health care. In the area of organ transplantation, the Uniform Anatomical Gift Act (UAGA) and the National Organ Transplant Act (NOTA) are intended in part to ensure this kind of equity of access to organs [4]. An important purpose of NOTA was to prohibit the assignment of a monetary value to an organ in order to prevent the commercialization of organs, thereby ensuring some level of equity of access to organs—and by extension to organ transplantation. Discrimination in access to deceased donor organs based on the socioeconomic status of the transplant candidate is prohibited. Title III of NOTA on the “Prohibition of Organ Purchases” states that it is “...unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce” [5].

It is in part because of this ban on socioeconomic discrimination that organ transplantation enjoys a privileged position with regard to the presumed fairness of its access system. It is often viewed as one of the only arenas in health care in which everyone has an equal opportunity of access, regardless of race, gender, socioeconomic status, celebrity, etc.—despite an absolute scarcity of resources.

There are currently more than 96,000 people listed on the United Network for Organ Sharing (UNOS) deceased organ donor waiting list, all of whom are waiting for an organ from the approximately 6,000 deceased individuals who donate organs in the U.S. each year [6]. A recent description of the UNOS waiting list and organ distribution system exemplifies the perception of the system's impartiality and fairness:

The rich ones don't get a leg up by mounting publicity campaigns or bribing doctors on the side. The poor ones don't have to worry because they know the list guarantees them an equal opportunity to live. There is no public outcry that the chief executive officer or celebrity has a secret edge over the others on the list [7].

The focus on equity and equality of access to organs is understandable given the persistent and critical scarcity of organs; however, it has overshadowed other critically important justice-related problems facing the transplant community. For instance, attention is often skewed to the particular ways in which the wealthy can leverage their socioeconomic status to gain access to organs, for example, by purchasing them. While it is true that attention should be paid to issues of unequal access to organs based on the greater advantages that wealthier transplant candidates have, the current national focus on access to organs only—and to deceased donor organs in particular—as a measure of equality of access to organ transplantation misses a larger and more pressing issue of inequality at stake in the area of transplantation: that of inequality in access to *successful organ transplantation*.

### **Only the appearance of equity**

Indeed it may at first appear that any problems related to equity and equality of access to organ transplantation are related almost solely to this organ shortage. That is, one might think that if the supply of organs were adequate to meet the demand for them, everyone who needed organs could have them, and questions of equity and equality of access would become largely irrelevant, as they have in the case of dialysis. This, however, is mistaken; equal access to organs does not mean equal access to organ transplantation. Even if there were a sufficient supply of suitable organs for transplantation, the reality is that the uninsured, underinsured and the poor do not currently have an equal opportunity to fully realize the benefits of organ transplantation because they do not have equal access to very expensive and necessary post-transplant immunosuppressant medications. Looking upstream as Daniels suggests, it appears that the wealthy and well-insured do have a socioeconomic advantage over others on the national waiting list precisely because

they can afford the necessary immunosuppressants. Without this medication, an equal opportunity to live cannot be guaranteed, even with a new organ.

The financial burdens associated with access to post-transplant medications can be significant. For example, kidney transplant recipients who qualify for Medicare coverage based solely on end-stage renal disease (ESRD) currently receive 80-percent coverage for immunosuppressant medications for a maximum period of 36 months. Given that the average half-life of a deceased donor kidney transplant (i.e., the point at which 50 percent of the organs will have survived and 50 percent will have failed) is 10 years and the average cost of the immunosuppressant medications is approximately \$1,500 to \$2,000 per month, even with ESRD Medicare coverage, poor kidney transplant recipients can expect to face medication costs of \$300 to \$400 per month for the first three years of their transplant and \$1,500 to \$2,000 per month thereafter, or as much as \$182,400 over 10 years in costs not reimbursed by Medicare [8].

A potential transplant candidate with ESRD on Medicare and employed fulltime earning the 2007 minimum wage rate in Illinois of \$6.50 per hour can expect to spend 26 to 35 percent of her pretax income on these medications alone for her first three years post-transplant. (And that's assuming she is able to continue employment with minimal interruption from her organ transplant procedure and has no supplemental insurance). After paying for her medications, she will have a pretax monthly income of between \$737.50 and \$837.50. Once Medicare coverage ends after three years, even assuming no increase in the costs of immunosuppressant medications, the monthly costs for the immunosuppressant medications necessary to maintain organ function will exceed her monthly income [9].

The costs of post-transplant medications pose a real and significant barrier to successful organ transplantation based on the socioeconomic circumstances of the recipient. This barrier is not neutral; the wealthy do have an edge and the poor are not guaranteed an equal opportunity to live. In some cases, these costs prevent patients who are otherwise medically good candidates for transplantation from making it onto the national deceased organ donor waiting list, either by their own choice or based on the recommendations of their health care team. Those who do get on the waiting list and receive a deceased donor organ transplant but cannot in the end afford the necessary medication will inevitably experience organ failure. Among the survivors, some will go back on dialysis and possibly back on the national deceased donor organ waiting list. Many will die while waiting on the list; others will simply wait to die. Poverty is not only a significant barrier to organ transplantation, it is in effect a de facto contraindication for it.

Even if we could immediately and successfully implement measures to ensure that the poor have an equal opportunity to access suitable organs for transplantation, the reality is that the poor do not currently have an equal opportunity to access the necessary postoperative immunosuppressant medications to maintain and fully realize the benefits of organ transplantation. In addressing solutions to the problem

of access to organ transplantation, it is important to focus on the full scope of the problem in both its pre- and post-operative aspects. In the context of organ transplantation, justice requires both equal access to organs *and* equal access to the medications needed to maintain those transplanted organs. The current inequities in access to successful organ transplantation based on the socioeconomic status of potential transplant recipients do not assure fair equality of opportunity and thus are fundamentally unjust. The structural inequalities inherent in the larger health care and social systems in which organ transplantation takes place are not impartial but pose very real barriers to access based on the socioeconomic status of potential organ transplant candidates.

Equal access to successful transplantation, regardless of the socioeconomic status of the potential organ transplant recipient, would at minimum require guaranteed long-term access to post-transplant immunosuppressant medications—like the guaranteed access to dialysis currently provided by the federal government. Optimally, it would require significant changes to the fundamental structural inequalities inherent in the larger health care and social systems. Right now the only thing that the poor are guaranteed is that there will still be a spot open for them at the dialysis center if and when their transplanted kidneys fail because they cannot afford the necessary immunosuppressant medications to maintain organ function. When one looks upstream from the point of access to organs, one sees that the current system is not impartial. Moreover, its partiality is not just.

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