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POLICY FORUM

Consumerist Responses to Scarcity of Organs for Transplant

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Introduction

In March 2009 Steve Jobs, then a northern California resident, flew to Tennessee to receive a liver transplant from a deceased donor [1]. Jobs's choice as a consumer to travel to a distant transplant center to improve his chances of receiving a lifesaving transplant focused national attention on patient choice and allocation of the limited supply of organs. Although Jobs's transplant was performed in compliance with all existing policies and procedures, its success highlighted vast geographic and economic disparities in access to transplantation.

The Current Situation: Geographic Disparities

Despite national efforts to increase donation rates, the demand for deceased-donor organs for transplantation continues to vastly exceed the available supply [2]. Because organ allocation systems operate primarily on a "local-first" basis, the impact of the organ shortage is far from uniform.

In general, organs are initially distributed to transplant candidates within the geographic region, called a donor service area (DSA), in which the organ was recovered. These 52 DSAs were defined by the Centers for Medicare and Medicaid Services and include all acute care hospitals in the region. If the organ is not accepted by a transplant center in the DSA, it is offered more broadly to centers within the United Network for Organ Sharing (UNOS) region. There are 11 UNOS regions that generally include several DSAs. If the organ is again declined in the region, it is offered nationally. This pattern of allocation varies by organ type and certain classifications of possible recipients (e.g., liver transplant patients with fulminant hepatic failure).

Under current policy, available liver grafts are allocated within a given region on the basis of disease severity, as assessed by the Model for End-Stage Liver Disease (MELD) score. In densely populated regions, like California, patients must be very ill to receive an organ, while, in regions with fewer waitlisted people per available organ, those with less severe illness (i.e., lower MELD scores) receive transplants, which results in a marked reduction in waitlist mortality and reduced cost at the time of transplantation and beyond [3]. These differences mean that the transplant center at which a patient is listed substantially influences waiting time and chance of death [4, 5]. Jobs chose to be listed at the University of Tennessee because patients at that center receive transplants with substantially lower MELD scores than patients in California.

Similar geographic disparities exist in kidney transplantation, for which waiting times vary from 18 months to more than 8 years depending on where one lives in the U.S. [2, 6]. A 2007 study by Ashby et al. concluded that wait times for kidney transplants in different regions vary from “60 percent lower to 150 percent higher than the national average (RR = 0.40–2.50), after adjusting for patient age, race, ethnicity, gender, ESRD cause, wait-list year, comorbid conditions, insurance type, blood type, PRA and HLA antigens” [6]. Patients with ESRD on long-term dialysis have higher risk of mortality, reduced quality of life, and higher overall health care costs than transplant recipients [5, 7].

A number of factors contribute to these discrepancies, including regional differences in the supply and demand for donor organs [8], centers’ organ acceptance practices [8], the geographical boundaries of UNOS transplant regions and donor service areas (DSA) within them [9, 10], and the size and characteristics of the potential donor populations [8].

In response to these observed discrepancies, the Department of Health and Human Services charged the transplant community in 1998 with ensuring that “allocation of scarce organs will be based on common medical criteria, not accidents of geography” [11]. Despite this guideline, few changes in policy have been implemented to alter the way organs are distributed with the goal of reducing regional disparities.

The Consumerist Response to Geographic Disparities: Leveraging Economic Disparities

This inequality in access has encouraged patient consumers to take their fates into their own hands by acting as domestic transplant tourists. Traditionally, the term “transplant tourism” describes the practice of traveling from a developed country to an economically disadvantaged nation to purchase access to the latter’s supply of organs, generally living-donor kidney and liver transplants. This practice has been widely criticized by the transplant community as economically exploitative [12]. Today, the term is no longer restricted to international travel. There is ample evidence that certain U.S. patients are able to seek services strategically from centers with access to more favorable organ supplies [13]: historically, 5–6 percent of patients awaiting deceased-donor kidney transplantation have elected to be evaluated and placed on more than one waiting list, which is permitted if separate donor services areas serve the centers [9].

Who are these patients? Axelrod et al. demonstrated that it is patients with high socioeconomic status who travel between DSAs [13], resulting in a 74 percent increase in access to transplantation and a 20 percent reduction in mortality after listing [14]. Merion et al. “found that, all other factors held constant, the odds of multiple listing were significantly higher for younger patients, males, whites, and those from higher-income areas, compared with older patients, women, nonwhites (except Asians), and those from low-income areas, respectively” [15].

Transplant transportation companies have sprung up, allowing patients who can access their services to escape the negative effects of discrepancies in waiting time for organ transplantation by selecting distant transplant centers with more favorable organ supplies. Currently, the average transplant candidate selects a secondary center 135 miles from the original listing center or approximately one day's drive [15]. Such companies aim to facilitate distant listing far from the patient's residence, in the vein of Steve Jobs. One such company, OrganJet, educates patients about multiple listing and where they can multiple list, assists patients in deciding whether they should transfer their wait times, and aids in patient transfer via car or commercial or private airplane for less than the price of chartering a private jet [16].

Ethical Implications

Empowering (some) patients to act as consumers and select the most favorable transplant centers does not address foundational problems underlying geographic disparities. A 2004 study by Merion et al., demonstrated increasing multiple or distant listing will not ameliorate geographic inequality in organ allocation.

Median waiting times for kidneys...at OPOs [organ procurement organizations] with the lowest and highest median waiting times demonstrate more than 10-fold and 22-fold differences, respectively [from the overall median waiting time]. The effects of multiple listing, as currently practiced, appear quite modest in comparison. In fact, regional disparities in waiting time would still dwarf the impact of multiple listing even if its use were, for example, to double

from 5.6 percent in 2004 [17]. Thus, one can see that empowering patients to act as consumers and place themselves on multiple lists does not significantly reduce current inequality in access to transplantation. Even after accounting for multiple or distant listing, patients in well-supplied regions (also known as "fly-in" regions) often still have shorter wait times than patients in "fly-out" regions (e.g., California) [18].

Furthermore, multiple listing exacerbates economic disparities. Patients with fewer monetary resources are substantially less able to travel for organs. For patients with ESRD, for example, commercial insurance covers the first 30 months of dialysis, after which Medicare, through the ESRD entitlement, becomes the primary payer. Dialysis costs are estimated to be \$80,000 per year [19]. It is well documented that transplantation is more cost-effective than dialysis [20]. While private insurers may elect to reimburse for travel to available organs, it appears unlikely that Medicare or state-based Medicaid programs will support organ recipient travel. This significantly limits who will be able to act as consumers in the transplant arena. Less affluent patients interested in pursuing this option face significant barriers to multiple or distant listing, including fewer financial resources to devote to travel and less ability to withstand loss of wages and separation from a support system.

Privilege, not just money, may block access to multiple listing. Since 2005 the Organ Procurement and Transplantation Network has mandated that transplant centers inform all patients of their right to multiple list or transfer their care to a different transplant center without loss of accrued waiting time. Additionally, in 2007 the revised CMS conditions of participation required transplant centers to inform patients of their right to be on more than one list [21]. However, the process is logistically complex, which may make it more difficult for those with less health literacy or privilege to navigate.

It is important to note that all travel between DSAs is not a consequence of differences in the organ supply. Patients may travel to distant centers for specific clinical expertise, proximity to family for support, or when directed by their insurance providers. Regardless, all are benefits that accrue to patient consumers with the resources to select any transplant center in the United States.

Ultimately, there is a growing body of evidence to support the conclusion that high socioeconomic status, private insurance coverage, and residence in regions with reduced access to deceased-donor organs are each associated with travel between DSAs and a reduction in mortality [14]. Consequently, while the impact of patient consumerism is immense throughout the U.S. health care delivery system, its impact is perhaps most evident in transplantation, where patient affluence and the choice it affords directly affects patient mortality.

Furthermore, while moving people off an overcrowded transplant list may benefit others on that list by decreasing wait time, it lengthens the wait time of those on the wait list in the “fly-in” region. This means transplant centers in the “fly-out” region that lose low-risk, revenue-generating patients—those who are relatively healthy and covered by commercial insurance—have less revenue to offset the expense of caring for lower-revenue patients (e.g., those with Medicare coverage), possibly jeopardizing those patients’ access to care.

Conclusion

The advent of companies that facilitate multiple listing and travel for organs should alert the transplant community to the expanding ability of a select subset of patients to exploit persistent inequalities in the transplant system. Since the 1998 DHHS final rule, no steps have been taken to alleviate these geographic inequities. A 1999 IOM report recommended that a new, quantitative system of setting priorities based on medical criteria be applied uniformly across geographical areas with populations of roughly nine million, a system that would effectively supersede UNOS’s regional structure, but it has never been adopted [22]. Ultimately, the most equitable solution will require a comprehensive policy that expands the boundaries over which organs are allocated. Patient consumerism in the transplant arena reveals a system rife with disparities in access. In this context, patient choice means that only those candidates with extensive resources are able to escape accidents of geography.

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