

Is it ethical to prioritize patients for organ allocation according to their values about organ donation?

Because the supply of deceased donor organs fails to meet demand, patients needing a transplant frequently have lengthy waits or die while waiting. In an effort to reduce waiting times, the concept of "preferred status" has emerged. In the United States, preferred status has taken the form of a community of individuals called LifeSharers. Using directed donation, this group aims to facilitate priority organ allocation to its members—people who have agreed to be organ donors. Such preferred status programs increase societal awareness about organ donation and transplantation, but they are not without ethical controversy, as some term them "clubs." In the case of LifeSharers, the potential to increase the pool of deceased donor organs is a worthy goal that would benefit the community of patients awaiting transplantation, not just LifeSharers members. (*Progress in Transplantation*. 2006;16:170-174)

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Each year, thousands of patients who are on the United Network for Organ Sharing (UNOS) transplant waiting lists die, as the number of allografts that become available do not meet the demand. Some patients wait months or years for an organ, depending on blood type, body size, geographic location, and organ needed.¹⁻³ As of December 1, 2005, there were more than 90 000 people waiting for an organ transplant in the United States, and some of these patients need more than 1 type of organ.⁴ Yearly, there are approximately 6300 deceased donors who provide an average of 3 organs for transplantation.⁵ UNOS estimates that roughly 50% of eligible deaths result in organ donation.⁵ Further, donation rates have increased only 3% each year from 1994 to 2003,⁶ despite efforts to educate society about the need for organ donation,⁷ and the use of donor registry campaigns at United States motor vehicle registration offices.⁸

As patients wait for donor organs, they risk further clinical deterioration that can render them unsuitable for transplantation. To address these lengthy waiting periods, some patients seek living donors or bridging devices.⁹ Some patients use the media^{10,11} or the Internet to announce their organ need.^{12,13} Another option is multiple listing; that is, placement on waiting lists at numerous hospitals to increase the chance to receive a transplant.^{14,15} This latter option is usually available only to those who have the financial means for multi-

ple transplant candidacy evaluations and live within a short distance from multiple transplant centers, or have the ability to hire charter aircraft for transport on short notice when an organ becomes available.

Prioritizing Organ Allocation

Several models of priority organ allocation (preferred status) have been proposed in the recent past, the first in the form of a letter to the editor in the *Wall Street Journal*. In this letter, attorney Jonathan Kaufelt proposed that a way of increasing organ donation would be to give transplant preference to those who have registered to be organ donors.¹⁶ This model has also been proposed by others.¹⁷⁻¹⁹ An extreme form of this concept has been proposed by Rupert Jarvis, a former researcher at the University of Swansea (United Kingdom).²⁰ He argues that in a setting of scarce organs, only those who have registered their desire to be an organ donor should be allowed to be organ recipients. In all of these proposals, the central theme is that those who do not agree to participate in organ donation are free-riders—people willing to receive organs without being willing to give them. All proposals also project that the concept of preferred status will result in more people registering to be organ donors so as to have a competitive edge over others if they ever need a transplant.

In reality, preferred status for those willing to be organ donors already occurs in the United States and

elsewhere. In Singapore, the government enforces a 1987 law that mandates priority organ allocation to those who opt-in as organ donors.²¹ Eurotransplant kidney allocation procedures reflect on the ratio of donations and transplantations occurring in each member country (Austria, Belgium, Germany, Luxembourg, The Netherlands, and Slovenia) to create a balance sheet. A negative balance means that the country is procuring more organs from its residents than it is transplanting. The patients in each country receive point allotments that reflect on the country's own kidney donation rate.^{22,23} Of note, it has been posed that in addition to the points based on the country's donation rate, bonus points be allotted to patients who had expressed personal willingness to be organ donors,¹⁷ but this has not been adopted.

In 1993, UNOS expressed concern that preferred status for those willing to be organ donors could create the perception that organ donation status is related to a person's moral worth, even though in reality, signing up for organ donation is a social contract.²⁴ Further, they fear that preferred status for those registered as organ donors might be the beginning of a trend for other types of moral worth variables to enter the organ allocation equation. Others have had similar fears that focus on preferred status reduces the "pure charity" of organ donation to a form of exchange—the net effect being a tarnishing of the altruism of organ donation.²⁵ Even with their concerns, UNOS did pose that a trial of preferred status could be employed; however, there are no reports that such a trial was ever initiated.

Although UNOS does not give preferred status to those who have registered as potential deceased organ donors, UNOS does give organ allocation preference to people who have been living donors (kidney, liver segment, lung segment, partial pancreas, small bowel segment).²⁶ Specifically, 4 extra points are given to such individuals if they become listed for kidney transplantation themselves. It would seem that UNOS could extend the same concept to other organ transplantations. Although the listing systems are different across organ types, it is likely that a similar conceptual approach could be created. Their choice to recognize only living donors for prioritization and not those who consent to be deceased donors may reflect the fact that these individuals have subjected themselves to personal risk (while alive) for the benefit of others. The bonus points allocated by UNOS are similar to the point allocation scheme argued for by Gubernatis and Kliemt¹⁷; namely, those who have been living kidney donors would receive the most bonus points when they, themselves, are in need of kidney transplantation.

The LifeSharers Model

An innovation in preferred status is the directed donation plan designed by an organization called Life-

Sharers.²⁷ Directed donation is allowed by federal and state law (and UNOS), although some restrictions may apply in certain states. Founded in 2002, LifeSharers is a nonprofit voluntary network of organ donors. Members promise to donate their organs upon their death, and they give fellow members first access to their organs. LifeSharers applies only to deceased donation. As the member pool grows, members themselves have an increasing chance at receiving a donated organ if they should ever need one. Individuals registered with the organization carry a wallet card that signifies their directed donation to LifeSharers members as first priority. Individuals can also attach an addendum to their advance directive/durable power of attorney documents indicating their membership and wishes about directed donation. A phone call to LifeSharers will inform transplant teams and donor families about current LifeSharers members who are in need of a donor organ (in order of their ranking on the UNOS waiting list). If there is no match, the organ(s) are then allocated to nonmembers. Children can be members if they are enrolled by a parent or guardian.

Currently, about 70% of patients receiving organs from deceased donors in the United States are not registered as organ donors themselves.²⁷ The foundational philosophy of LifeSharers is that giving organs first to those consenting to be organ donors creates the incentive for people to become organ donors. Potential recipients must hold LifeSharers membership for 180 days before they qualify for first access to organs of other members. This waiting period discourages people from waiting to join only when they learn they need a transplant. As of November 30, 2005, LifeSharers reports nearly 3500 members, with 22 of these members listed on the UNOS transplant waiting list. These listed members will get first chance at any organs donated by deceased LifeSharers members. With the current membership volume, there is roughly a 16% chance that one or more LifeSharers members will die in the next 12 months in circumstances permitting recovery of an organ. LifeSharers projects 40 000 members by summer 2006 because of their plan for increased marketing of their program. At that volume, the potential for donation increases from 16% to 90%. This would facilitate the first member-to-member transplantation by possibly 2007.²⁸

LifeSharers presents a level playing field for all members as the "benefit" offered is the same for everyone, no matter their age, gender, ethnicity, religion, or financial status. In fact, the only benefit is the potential for priority organ allocation amid the concept of directed donation. There is no membership fee to join the organization, and no option to pay for additional benefits. In addition, the LifeSharers philosophy can potentially motivate people to become organ donors, something that benefits even nonmembers who are waiting for a

transplant, because they too are potentially exposed to more organ matches. A net increase in organs available for transplantation will exist, because not all organs donated by LifeSharers members will match with LifeSharers patients who are waiting for transplants.

Ethical Complexities of Preferred Status

Some transplant centers have been accused of "gaming" waiting lists and inflating illness severity so that patients are moved toward the top of the waiting list.^{29,30} In addition, physicians and patients themselves can potentially reduce transplant waiting times using a variety of techniques. In general, methods of jumping the queue work by favoring the patient at hand over other patients. Further, these methods generate publicity (good and bad) about organ donation and transplantation.

Individuals could be opposed to organ donation (eg, organs are removed and not replaced), but not to transplantation (as the recipient numerically maintains all body parts). This group of individuals would be disadvantaged by a program such as LifeSharers because they would not be eligible for priority receipt of an organ; however, they could potentially benefit by the mere existence of LifeSharers in that the program is increasing the volume of the organ donor pool in general, which potentially benefits everyone waiting for a transplant (as there are more potential matches for both LifeSharers members and nonmembers).

Another group to consider is those who lack the decision-making capacity to consent to organ donation.³¹ Although the LifeSharers program allows parents to consent on behalf of their children, it is unclear if surrogates (parent/guardian) can consent for adults who functionally cannot give voluntary informed consent. Some state courts have determined that organ donation by mentally impaired adults is legal and such donations have occurred.³² If this group cannot attain membership, then they lose the chance at organ allocation prioritization. Their only potential benefit is an increase in the chance at transplantation due to a net increase in the donor pool volume.

The 180-day waiting period required by LifeSharers deters people from seeking membership when they know they may need an organ in the very near future. On the other hand, the waiting period does not appear to contain an exception clause for people who suddenly, urgently, and unexpectedly need transplantation because of trauma or fulminant organ failure. These people would not be eligible for a LifeSharers-directed donation because their membership would not be considered active (for preferential organ allocation). It would seem that allowing such an exception clause to LifeSharers membership would be ethically feasible.

LifeSharers does not consider a person's medical history relevant to organ donation registration or mem-

bership in their organization. The focus is the members' willingness to donate, not their actual ability to donate. This, however, raises the issue of donor registration by individuals who know they are not candidates to donate an organ, but who might be candidates to receive an organ. These individuals could potentially "game" the system by unfair prioritization. These cases are essentially a moving target because medical exclusions for donation are likely to change over time as the criteria for "marginal" organs expand.³³ Also, individuals who at the time of registration might indeed be suitable candidates for donation may later experience medical complications that render them unable to be donors; however, their previous expressed commitment to donation should not be ignored if a need for a transplant arises, because they personally have not changed their values about organ donation. These individuals should be allowed priority organ allocation. Once committing to registration, donors could remain on the registry as long as they wish, even after they cease to be eligible donors, so that they retain their priority allocation status. Conversely, individuals should be free to remove their names from the donor registry at any time, but they should lose their opportunity at priority organ allocation because of the fact they altered their values and reversed their commitment to the concept of organ donation.³⁴

Should Medical Urgency Be Relevant?

LifeSharers does account for the medical urgency of its members who are in need of transplantation in that those members who have greater urgency and are a clinical match receive organ allocation prioritization among the member pool. LifeSharers, however, does not consider the medical urgency of nonmembers because nonmembers do not share the value commitment to organ donation. It would be possible that a LifeSharers member who is listed for a transplant might receive a directed donation from a deceased LifeSharers member and the recipient may be healthier than the nonmembers who are also in need of an organ transplant. This fact is no different from UNOS permitted directed donation transplants that currently occur outside of the LifeSharers member network.³⁵ Any ethical arguments against a preferred status model that does not reflect on medical urgency would also have to address the fact that directed donations currently allowed by UNOS do not reflect on medical urgency. In these latter cases it is usually a personal relationship or emotional feelings that are driving the donation—matters not equivalent to or necessarily reflecting on medical urgency, but matters that prompt organ donation in some cases.

Free Riders and Society

The concept of free riders is ethically troublesome. An analogy is the UNOS restriction on the

yearly amount of transplantations allowed to nonresident aliens.³⁶ Many of these recipients are people who come to the United States for the sole purpose of receiving an organ transplant—unlikely to ever have been registered as organ donors in the United States (givers), rather only participating as recipients (takers) who return to their country of origin after transplantation. Similarly, organs from deceased donors in the United States can be exported to another country only if no suitable match is found in the United States. These policies support the notion of a “transplant community” with a foundation that reflects on the concepts of solidarity and reciprocity. These concepts are also foundational to models of preferred status that are based on organ donor registration.

In a setting in which preferred status is operational amid an allocation program that does not consider medical urgency, those who actively choose not to register as organ donors place themselves in a position of lower priority for organ allocation. Because organ transplantation is not a human right, and organs are very scarce, viewing free riders as having a lower priority in organ allocation is ethically permissible. Although the majority of polled members of the International Society for Heart and Lung Transplantation disagree,³⁷ those with bona fide religious and/or moral objections to donation should not be subjected to the rules of a preferred status system, because they should be viewed as having a “special value” that is appropriate to respect.³⁸

People who cannot themselves consent to organ donation (children, adults lacking decision-making capacity) should also not be subjected to the rules of a preferred status system. Families may refuse to allow their children to be deceased organ donors, yet the child might hold values for organ donation that cannot legally be expressed because of minor age. The same can be said for guardians who refuse to allow adults under their charge to be deceased organ donors. These incompetent adults also cannot give legal consent to donate; thus, donation status should not be a variable to their transplant listing status. There should be no room for third parties to make decisions on behalf of patients who cannot decide for themselves, if those decisions could lower patients' waiting status.

In 2003, Dr Aaron Spital conducted a national telephone survey with regard to public attitudes about the concept of preferred status in organ allocation.³⁹ Specifically, 1014 adults were asked, “Should people who have agreed to donate their organs after death be given priority to receive organs if they themselves should ever need them over people who have not agreed to donate their organs after death?” The majority of respondents reported “yes” or “probably yes” (53% of the total responses). Forty-one percent responded that priority should not or probably should not be given to those who would donate. Interestingly, those who

were college educated were less supportive of this plan than those who were less educated. Younger people were generally more supportive of the plan than older people. Thirteen years earlier, UNOS conducted a similar telephone survey involving 800 adults.⁴⁰ Their survey was worded such that bonus points allotted for willingness to be an organ donor would not override situations of medical urgency. Of the 52% of respondents who supported financial or nonfinancial incentives to increase the rate of organ donation, most indicated they favored preferred status as the form of incentive. The results of these studies indicate that society would, at a minimum, likely support a UNOS sponsored trial of a preferred status program. The program timeline should be of sufficient length so as to allow for monitoring of donation trends.

Conclusion

Increasing the number of organ donors without the aspect of changing the order of those waiting in the queue would be the optimal approach for transplant medicine; however, historically this has not occurred and donor projections (3% yearly increase) do not predict that such will materialize. Faced with dismal organ donation rates and projections, the LifeSharers approach is ethically permissible, yet it could be enhanced by a waiting period exception clause as discussed above. Although some may term LifeSharers a “club,”⁴⁰ it is nonetheless a club that is open to children as well as adults with decision-making capacity, with no membership fee. It also avoids the ethically problematic matters of active solicitation of donors using the media, as well as financial incentives⁴¹ for organ donation.

Does LifeSharers play favorites? Yes. And in the case of organ scarcity it is appropriate to favor fellow organ donors (actual or prospective) over free riders. When it is time to allocate a scarce resource, it is fair to assign priority to people who are willing to both give and receive. Preferred status does not need to operate merely as a tiebreaker when all other variables are equal. Further, preferred status should not cease to operate when nonpreferred patients are more severely ill, because this would devalue willingness to donate.

Disclosure

The author is a member of LifeSharers but has no other relationship to the organization. The author is not a consultant for LifeSharers and is not on its Board of Directors. The arguments expressed are those of the author. The manuscript was not commissioned by LifeSharers. No Institutional Review Board review required.

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