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*The Moral Status of Preferences for Directed  
Donation: Who Should Decide Who Gets  
Transplantable Organs?*

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**Introduction**

Bioethics has entered a new era: as many commentators have noted, the familiar mantra of autonomy, beneficence, nonmaleficence, and justice has proven to be an overly simplistic framework for understanding problems that arise in modern medicine, particularly at the intersection of public policy and individual preferences. A tradition of liberal pluralism grounds respect for individual preferences and affirmation of competing conceptions of the good. But we struggle to maintain (or at times explicitly reject) this tradition in the face of individual preferences that we find distasteful, suspect, or even repugnant, especially where the broader social good or respect for equality is at stake. Directed donation presents us with such a dilemma: can we uphold the right of self-determination through respect of individual preferences regarding disposition of transplantable organs<sup>1</sup> while at the same time maintaining an allocation system that reflects values of equity and justice claimed to underlie the socially negotiated practice of transplantation?<sup>2</sup> Or are some preferences simply to be deemed unethical and not respected, even if that leads to a reduction in the number of transplantable organs available and to an apparent disregard for the autonomous decisions of the recently deceased?

Directed donation occurs when a person requests that transplantable organs be given to a particular candidate or class of candidates after his or her death.<sup>3</sup> Informal reports indicate that such requests occur fairly infrequently, although increased public education about organ donation and protocols such as controlled nonheartbeating organ donation (NHBOD) could result in more consideration about who specifically might be benefited by a gift of transplantable organs.<sup>4</sup> More importantly, directed donation prompts reflection on the complex of principles underlying the policies inherent in the current organ-donation system and its historical development in the United States.

I present an argument against permitting most forms of directed donation, focusing on utilitarian justifications for policies on directed donation because these are the most common forms of argument utilized in this debate.<sup>5</sup> Based on a moral framework drawn from political philosophy and moral theory

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regarding preferences, I provide a taxonomy of impermissible (and limited permissible) instances of directed donation given the current structure of the U.S. organ-allocation system overseen by the United Network for Organ Sharing (UNOS).<sup>6</sup> The implications of my argument for the existing organ-allocation system as overseen by UNOS also are briefly explored, particularly regarding prioritization of local candidates and the effects of geography on organ distribution.

## Background

What are the general principles underlying UNOS policies regarding allocation of donated cadaveric organs? When a cadaveric organ is donated, it is offered first to the person who is listed at a transplant center in the local area who is a match based on biological characteristics and who fulfills some combination of other attributes (e.g., most amount of waiting time, urgency for some organ types, and so on), with an exception being perfectly matched kidneys.<sup>7</sup> If there is no one waiting in the local area, then the organ is offered based on the same matching principles in the region (which generally is defined historically by the existence of an organ procurement organization [OPO]), then nationally.<sup>8</sup> With regard specifically to directed donation, the UNOS board approved a statement in accordance with a recommendation by its ethics committee that “donation of organs in a manner which discriminates for or against a class of people based on race, national origin, religion, gender, or similar characteristics is unethical and may not ethically be accepted by UNOS members or transplant professionals.”<sup>9</sup> However, it is difficult to determine whether such a recommendation is enforceable. Currently, OPOs respond differently to directed donation requests. A few states have prohibited directed donation, but most of these have not explicitly changed their donation laws, which reflect the Uniform Anatomical Gift Act (UAGA), which allows directed donation (section 4[c]). Although several states have deleted references to directed donation, their laws leave it unclear whether it is not permissible or simply not encouraged. Most importantly, particularly given the range of laws and public opinion on the subject, the moral reasoning underlying the UNOS policy has not been provided.

Many instances of directed donation intuitively seem unproblematic to us. Consider the following: “A daughter’s last gift: A young woman killed in a car accident saves her father’s life by donating her heart for a transplant.”<sup>10</sup> Clearly tragic, but unethical? How about “Transplant of son’s eye gives sight to mother”?<sup>11</sup> These donation decisions closely parallel the sorts of decisions made by living organ donors. Perhaps if all instances of directed donation were of this sort, our moral sensors would not go off.

Concerns are immediately raised by other sorts of requests regarding directed donation, especially where it seems that the media is involved in promoting the cause of a particular waiting transplant candidate or where a family aggressively seeks a donor by publicly stressing that their family member is particularly needy. For instance, an example of what might be called “media abetted” allocation occurred when a family directed donation of their son’s heart to a teenager waiting in St. Louis about whom they read in their local paper. They reportedly selected him from among a group of young people in the same hospital waiting for heart transplants, because they were from the same town as the recipient.<sup>12</sup> In this class of cases, although the situations are indeed tragic

and there does not seem to be anything patently discriminatory about donors or their families directing donation of transplantable organs, it at least smacks of “gaming the system.” It is also interesting to note that the rhetoric surrounding many such cases seems to imply that certain candidates are in some way more deserving than others, or are “ethically special” in some way that make a personal appeal for a directed donation appropriate.<sup>13</sup>

A third class of cases arises when donors or their families direct organ donations toward or away from certain groups. A Florida newspaper recounted the story of a family who agreed to donate their son’s organs, but only if they went to people who were White like their son, reportedly in part because the man had been an active member of a White supremacist group.<sup>14</sup> This case led to a legislative ban in the state of Florida on directed donation to particular groups.<sup>15</sup> The article also recounts that a Nazi concentration camp survivor stipulated that none of her organs could go to people of German descent. These sorts of cases are more troubling to us and motivate an investigation of whether our moral intuitions can be grounded in a more adequate ethical framework through an examination of arguments regarding directed donation in the current bioethics literature.

## **Directed Donation Issues**

### *Organs as Social Goods?*

Eike-Hennner Kluge has argued that because organ donation must occur in a heavily institutionalized and social context, the gift of a donated cadaveric organ is “not complete within itself.”<sup>16</sup> Thus, because the process requires people other than donors and recipients for the procedure to occur and for the gift to gain its meaning and significance, the organ that as bodily tissue was merely a private good becomes a social good when it is a donated organ. Although it is clear that organ donation has a social character and there is a symbolic change of meaning that occurs when mere flesh becomes donated organ,<sup>17</sup> this argument fails to capture some of the salient facets of the situation. As a result, it provides a weak justification for prohibition of most forms of directed donation, particularly against utilitarian arguments in favor of directed donation to be described later. First, note that the social nature of organ donation is a contingent phenomenon, reflecting our current allocation system. Some economists argue that whether goods are public or private depends on the empirical question of how they are best marketed, which leaves most goods (including transplantable organs, it could be argued) in the realm of “ambiguous goods.”<sup>18</sup> Presumably, those in favor of a wholly or partially commercialized system for procurement and distribution of transplantable organs would agree.<sup>19</sup> More importantly, many undertakings are social—not only because they are socially embedded but also because they require others in order to attain completion—but do not necessarily result in the creation of social resources. An example is the bequest of material possessions after death via a socially recognized and enforced document such as a will. Directed blood donation is currently permitted (and encouraged) in many places. Although outsiders are required to draw, store, and transport the blood products, individuals’ desires to have blood from members of their family or community and to donate blood directly to particular individuals in need are often respected.<sup>20</sup>

Although there may be other reasons not to allow directed blood donation (e.g., to reduce perpetuation of misconceptions about “clean blood” and blood-borne disease transmission, especially given the extra costs involved in directed donation), Kluge’s argument based on the creation of social goods does not engage or address the most relevant ethical considerations.

### *Race-Based Allocation of Organs?*

In light of evidence that Blacks on U.S. kidney waiting lists wait almost twice as long as Whites,<sup>21</sup> even when the data are controlled for medical and geographic factors, Wayne B. Arnason has argued in favor of a policy experiment that would match Black donor kidneys with Black recipients based on standardized UNOS criteria but without consideration of waiting time, except in cases of Black-Black recipient ties. He claims that “the prospect of a black donor’s kidney finding its way into the body of a black recipient would *remove a disincentive* for black donors,”<sup>22</sup> while rejecting the idea that some form of “affirmative action” program for prospective Black recipients could be guaranteed to provide an incentive for increased donation given the currently available empirical evidence.<sup>23</sup>

Arnason’s argument is questionable for several reasons. First, he claims that there are exceptions to the impartial, condition-specific allocation system, and he relies on these as precedents for using allocation principles other than the point system for allocation; his examples include the permissibility of live, emotionally related donation, and the prohibition of exportation of organs outside of the United States and Canada. The former consideration will be discussed below, but suffice to say that the paradigm of living donation circumscribes a very specific class of permissible instances of directed donation.<sup>24</sup> The latter consideration theoretically is not an instance of *who* receives the organs (i.e., whether a donation is directed away from or toward a particular individual or group) because foreign nationals can be put on the UNOS transplant waiting list so long as they are listed via a U.S. transplant center, but *where* the transplant occurs. Second, his policy experiment relies on an unexplicated notion of how “race” would be determined, particularly problematic because an adequate scientifically or socially based concept of race has proven notoriously difficult or impossible to define.

### *Motivating Donors through Directed Donation*

Robert M. Sade recently has proposed a system for distribution of organs for transplantation, which he calls the Selection of Potential Recipients of Transplants (SPRT).<sup>25</sup> This system would allow donors or relatives of a medically suitable donor to choose a specific individual recipient or category of recipients to receive the donated organ(s), which he believes would reconnect the donor and the recipient, thus increasing donation by emphasizing the personal stake of the donor and/or the donor’s family in the donation process. As he admits, whether SPRT actually would result in an increase in organ donation is an empirical question best answered through pilot studies. But the form of his argument is of most interest because it relies largely on a utilitarian justification. He claims that such a system would maximize benefits—in this case, defined as the number of organs available for transplant together with recog-

nition and advancement of “personal values” of recipients—while minimizing harms, among which he includes disincentives to organ donation, including distrust of the current system. Perhaps at best this proposal might help to reinstate a broader idea of community that seems currently lacking due to this distrust and places us on difficult moral ground for making judgments about an individual’s willingness to donate. For as Richard Rorty has put it in a different context, “One cannot be irresponsible toward a community of which one does not think of oneself as a member.”<sup>26</sup>

Karen A. Korzick and Peter B. Terry briefly criticize Sade’s proposal against the background of various theories of distributive justice. However, they fail to provide an argument that the principle of justice should be the most relevant principle to consider when establishing policies for transplantation, particularly given Sade’s concern about distrust and lack of a unified community.<sup>27</sup> They also claim that under a system of utilitarian distributive justice, there can be no claims to individual rights. However, preference utilitarians would assert that justice in distribution consists in maximizing the extent to which people have what they prefer or want, even if the preferences of some fail to be satisfied. Sade (and some utilitarians) also could respond by claiming that, although individual rights do not count *qua* individual rights, fostering a political atmosphere that supports such rights often contributes to an overall maximization of benefit as compared to harm. Sade’s proposal leaves us with the currently unanswerable empirical question of what would happen under a directed donation scheme such as SPRT; in other words, whether benefit indeed would be maximized.

Of particular concern for making the judgment about degree of benefit is whether we consider these types of preferences to be personal (i.e., preferences focused on the individual’s own enjoyment of a good or an opportunity, say to express his wishes or to be memorialized after death) or external (i.e., preferences for the assignment of goods or opportunities toward or away from others). As Ronald Dworkin has argued, this distinction is all important to the utilitarian argument because a truly utilitarian distribution is also egalitarian and observes strict impartiality; thus external preferences that rely on political theories that are contrary to utilitarianism corrupt it.<sup>28</sup> If such external preferences are allowed to be decisive in a policy decision (such as one about the permissibility of directed donation), Dworkin claims, the fact that the policy makes a community better off in the utilitarian sense is no longer an adequate justification for disadvantaging some who should be treated as equals. Thus Dworkin’s argument is extremely useful in examining the case at hand, where utilitarian justifications are being used for policy decisions, complex preferences are at issue, and particular individuals (or classes of individuals) seem to be jumping the queue, violating basic principles of equity.<sup>29</sup> Therefore, the more interesting philosophical questions are how to understand people’s preferences as expressions of their conceptions of the good and when such conceptions should be accommodated, particularly in cases where it is difficult to disentangle personal and external preferences.

### **Permissible Preferences and Political Theory**

Returning to the main question: how should the organ allocation system be structured to accommodate (or rule out) preferences regarding the characteris-



tics or identity of an anticipated recipient of donated organs? To maintain or increase donation rates and public support for the transplantation process, it is essential to prioritize focus on the process that has established and oversees ongoing alterations in the rules governing the organ distribution system. An assumption underlying the UNOS policies is that persons may decline to donate if they perceive that the allocation system is not equitable or if persons in similar circumstances such as themselves may not be treated equitably in the allocation system. But how equity is to be defined is at least partially an empirical issue. Instances of partiality occur under the current system but are substantiated by largely, though not universally, shared principles concerning the appropriateness of such partiality. For example, all medical criteria for distributing donated cadaveric organs are in fact instances of partiality: they allow preference of one candidate over another based on factors that have been to a certain extent negotiated and codified in UNOS allocation policy.

Similarly, our moral intuitions suggest that donation to a particular emotionally or biologically related person is permissible, and even admirable. After all, when we permit living donation, we are in fact indirectly endorsing a form of directed donation. Therefore, it is inconsistent not to permit such donation following death, so long as there is a relationship between the individuals (along with criteria for assessing such a relationship, etc.).<sup>30</sup> To put it in utilitarian terms, the preference being expressed is a personal one, and it does not unduly corrupt the egalitarian basis of utilitarianism, because we in fact generally deem such a preference to be appropriate. In fact, we allow directed living donation precisely because of the partiality on the part of the donor for the recipient, which in turn engenders benefits to both parties because the donor serves his or her own interests (particularly if these interests are defined as including broader familial interests) by helping to save the life of a related other. Thus, cadaveric directed donations should be permissible provided that the recipient and donor are emotionally related.

Notice that merely coming to care about a potential recipient whom you see night after night on the local news does not count as a morally significant emotional relationship, or to put it in a slightly different way, does not provide grounds for appropriate partiality. Given that media access is not uniform, it is not appropriate to allow unequal access to publicity to result in unequal access to transplantable organs. The emotional appeal of those needing organ transplantation should be employed to prompt general interest in organ donation. To permit especially attractive (typically young, photogenic) potential recipients or VIPs to solicit or attract directed donors (and thus jump the queue) would unfairly disadvantage those who might be viewed in the glare of the cameras as less attractive candidates. In particular, it does not have the compensating ethical advantage that the emotionally related case does, because the emotionally related person's interests and preferences are directly and personally tied to the welfare of the potential recipient.

However, it is not so clear whether we should endorse living donation toward or away from certain groups. Our intuitions suggest that it is morally reprehensible, or at least suspect, to be willing to donate but refuse to allow the organ to go to members of a particular group, for example due to ageism, racism, sexism, religious or ethnic hatred, or because of perceptions about some diseases being self-induced. Dworkin's discussion of external preferences is particularly helpful here; suppose there is a situation where many individuals

who are racists express preferences that scarce medical resources be directed to a White man who needs them rather than to a Black man who needs them more (and that these individuals do not themselves need the resources, hence the preferences are not personal). As he states, "If utilitarianism counts these political preferences at face value, then it will be, from the standpoint of personal preferences, self-defeating, because the distribution of medicine will then not be, from that standpoint, utilitarian at all."<sup>31</sup>

It is less obvious how to articulate the moral ground for our different intuitions about honoring refusals of donation to members of a particular group versus honoring positive directed donations (e.g., choosing to donate to members of one's church or sorority, an extended family member, or someone in the local community), particularly when such preferences seem in part to be an expression of individual identity and a strong association with a particular group. It is at this point that political theory addressing mixed preferences (those that represent an intermingling of external and personal preferences) and respect for them within a broader sociopolitical structure becomes most relevant. In an article focused on the phenomenon of endogenous preferences, preferences that seem to adapt to a wide range of factors including sociopolitical and cultural context, legal and social rules, current information available, past choices, and so on, Cass R. Sunstein notes that "[i]t is one thing to affirm competing conceptions of the good; it is a quite another to suggest that political outcomes must generally be justified by or even should always respect, private preferences."<sup>32</sup> He argues that constraints on respecting preferences are appropriate even when the preferences reflect collective judgments (1) when the choice that would be eliminated by respecting the preference has some special character and especially if it is a part of deliberative democracy itself; (2) when the collective desires or preferences are objectionable or a product of unjust background conditions; and/or (3) if the collective preferences reflect a special weakness on the part of the majority. Thus directed donation to people who are not members of a particular group, for example, donation by a KKK member to "anyone but a Black or a Jew," should be impermissible. Such donations exhibit morally suspect or reprehensible value commitments and beliefs (what could be termed "inappropriate partiality") that could be argued to be objectionable in themselves, or at least a product of unjust background conditions. In themselves, such motivations exhibit a failure to respect individuals as equals, as worthy of equal respect and dignity, which it can be argued undermines the basis of utilitarianism. Permitting members of some groups to be passed over because of donor preferences and group affiliations would be unfair because it is not a case where personal or emotional ties or preferences trump our typical concerns about partiality, and hence the compensating ethical advantage discussed earlier is lacking. Such practices would likely exacerbate existing inequalities that could be viewed as part of the unjust background conditions against which these preferences have been formed, specifically in this case the late referral of members of minorities for healthcare and especially for transplantation.

So what are we to do about positive directed donation to members of a group, for example members of my faith, community, ethnic group, and so on? Respect for self-determination, individual values, expression of preferences, and partiality might suggest that such directed donation should be permissible.



However, for similar reasons to those suggesting it should be impermissible to allow directed donation away from certain people or classes of people, it should be impermissible to donate only to members of a particular group. If the ties of group relationship are sufficiently strong as to form the basis of friendship, love, or other emotional relation (i.e., appropriate partiality), then the prospective donor could presumably name the prospective recipient in his or her donor card. If the ties are not so strong and so personalized, then from the perspective of preserving a fair organ-allocation system and maintaining impartiality, donation to members of one group may be viewed merely as a surrogate for refusal of donation to another. In more formal philosophical terms, associational preferences are particularly dangerous, given that they often reflect personal preferences that are parasitic on external preferences, particularly in cases affected by prejudice.<sup>33</sup>

### Geography and Organ Distribution

Against the background of this discussion, consider the general UNOS cadaveric organ allocation policies. Notice that any "locals first" policy relies, in part, on the beliefs that (1) it is permissible (in the sense of being morally appropriate) to prefer to donate to members of your local community, and (2) people in fact prefer to donate locally. This line of reasoning, among others, was cited by UNOS in their 1991 report on the (lack of) feasibility of a national waiting list.<sup>34</sup> Relatedly, the policy statement indicated that many transplant professionals believe that more organs are donated for transplantation when organs are kept locally, and it might be the case that retaining organs locally encourages professionals to request donation more frequently.<sup>35</sup> It is not clear what public opinion actually concerning this question is; at least one survey found that 66% of people who had not yet signed donor cards would be more strongly influenced to become a donor by a policy that favored national distribution, and an OPTN poll in 1990 showed that over 75% of respondents disagreed with the statement that "donor organs should go to someone in the area where the donor lived."<sup>36</sup> Furthermore, offering organs locally means offering organs to those listed at local programs who in fact are not necessarily residents of the local community, given that many individuals are listed at programs not proximate to their residences and larger transplant centers attract candidates from a wide geographical area.

Ironically, the insight that UNOS relies on to justify its local rule may be used to undermine it. Such a local rule can only be ethically justified if it is assumed that each locality will be inclined, and roughly equally inclined, to look after its own members; that is, to exhibit partiality toward those listed at a local transplant center. Otherwise, access to a resource would depend on where one is lucky or savvy enough to be listed as a transplant candidate. But it is clear that there are differential donation rates around the United States, and greatly divergent densities of populations of candidates awaiting transplant in various regions.<sup>37</sup> Thinking about directed donation in terms of partiality and permissible preferences leads to the conclusion that so long as preservation or ischemic time is not at issue, any form of a "locals first" policy is ethically flawed because it assumes preference of donation to a particular group (i.e., local candidates), a conclusion that is neither empirically justified nor ethically grounded in terms of permissible partiality.

## Conclusions

Directed donation presents us with a classic dilemma—the clash of individual preferences and the right of self-determination with the values of equity and justice reflected in our public policies. I have provided an argument against permitting most forms of directed donation using a utilitarian justification, against a moral framework drawn from political philosophy and moral theory regarding preferences. However, suppose that not allowing directed donation leads to a decrease in the overall number of organs donated. Given that we are working within a utilitarian framework, we must consider the following question: what good can be supposed to arise from instituting and enforcing such a limiting policy? This question leads to a rather unexpected conclusion: not that we should consider allowing directed or otherwise restricted organ donations in all cases, but instead that the process surrounding policy development in transplantation must be more open for public scrutiny.<sup>38</sup> It is not enough to institute rules, however fair they may be. Morally adequate rationalizations for rules must also be formulated, debated, and well publicized. Such a process may have the compensating advantage of actually influencing and transforming people's preferences over the longer run, a goal that is claimed by some to be at the core of any political process:

... over time one will in fact come to be swayed by considerations about the common good ... one would have to invoke the power of reason to break down prejudice and selfishness. By speaking in the voice of reason, one also exposes oneself to reason. To sum up, then, the conceptual impossibility of expressing selfish arguments in public debate, and the psychological difficulty of expressing other-regarding preferences without coming to acquire them, jointly bring it about that public discussions lead to realization of the common good.<sup>39</sup>

And as much as it is a medical process, so too is transplantation a sociopolitical one that needs to reinstate the common good firmly at its core.

## Notes

1. For a brief argument in favor of allowing directed donation to particular individuals on the basis of donor autonomy, see: Fox MD. When an organ donor names the recipient. *American Journal of Nursing* 1996;96:68.
2. United Network for Organ Sharing. The UNOS statement of principles and objective of equitable organ allocation. *UNOS Update* Aug 1994:20-38. A summary of UNOS policies is available at: <http://www.unos.org>
3. For the purposes of this paper, I assume that the desire to make a directed donation is articulated by the prospective donor prior to death on a donor card or in some other manner, or is expressed by his or her family based on good evidence that the directed donation reflects the decedent's prior preferences. Hence I focus on preferences that seem to be objectionable not because of their origin (i.e., not out of concern that they have arisen nonautonomously or under inappropriate coercive influences) but on the more controversial category of preferences that seem to be problematic because of their content. This taxonomy is clearly articulated by Jon Elster in his *Sour Grapes: Studies in the Subversion of Rationality*. London/New York: Cambridge University Press, 1983:22.
4. Thanks to Lisa Parker for making this point. On NHBOD, see: Arnold RM, Younger SY, Schapiro R, Spicer CM, eds. *Procuring Organs for Transplant: The Debate over Non-Heart-Beating*

- Cadaver Protocols*. Baltimore: Johns Hopkins University Press, 1995; Institute of Medicine. *Non-Heart-Beating Organ Transplantation: Medical and Ethical Issues in Procurement*. Washington, D.C.: National Academy Press, 1997.
5. I do not address the wide array of nonutilitarian arguments (e.g., libertarian or rights-based justifications) for directed donation because most literature in favor of directed donation takes utilitarianism as its main defense. I also do not address the responsibilities or moral authority of healthcare professionals or individual donors at stake in directed donation, taking policy as my primary level of focus, though fairly obvious implications for these follow from my argument.
  6. This paper does not attempt to engage the issue of whether transplantation should in fact be a healthcare priority, and therefore the question of whether the current organ supply is indeed a "shortage" goes unexamined. For criticisms of this assumption, see: Fox RC. An ignoble form of cannibalism: reflections on the Pittsburgh protocol for procuring organs from non-heart-beating cadavers. *Kennedy Institute of Ethics Journal* 1993;3:231–40; Holmes HB. Closing the gaps: an imperative for feminist bioethics. In: Donchin A, Purdy LM, eds. *Embodying Bioethics: Recent Feminist Advances*. Lanham, Md.: Rowman & Littlefield, 1999:45–64.
  7. UNOS Policies, section 3.3, May 1988. A long-debated rule of the Department of Health and Human Services (DHHS) became effective March 16, 2000, which mandates organ distribution based on medical urgency without regard to location of organs/candidates (see DHHS 42 CFR Part 121, *Federal Register* 22 Mar 2000;65:15252). Also see, for example: HHS amends organ donor rules in face of criticism. *Washington Post* 19 Oct 1999:A7. However the actual policies to be implemented continue to be negotiated by the DHHS together with representatives from UNOS and the Institute of Medicine (IOM). See also note 2, UNOS 1994.
  8. This system is based the assumption that it is optimal not to transport cadaveric organs in order to reduce ischemic time and thus to reduce organ damage and waste. On debates surrounding appropriate ischemic time and their implications for transplant policy, see: Ankeny RA. Multiple listing: autonomy unbounded or a reasonable solution in light of organ scarcity? *Cambridge Quarterly of Healthcare Ethics* 1999;8:330–9.
  9. See UNOS Update 1994,10:9. Also see note 2, UNOS 1994.
  10. Hull JD. A daughter's last gift: C. Szuber receives heart of his daughter in a transplant operation. *Time Magazine* 5 Sep 1994:45; Father receives heart transplant from daughter. *New York Times* 26 Aug 1994:A14.
  11. *New York Times* 26 Mar 1994:A27.
  12. Sauerwein K. Family selects heart recipient, raises issues. *St. Louis Post-Dispatch* 1 May 1996:A1; Librach PB. Five youths here in need of heart transplants: "We've never had that many," doctor says. *St. Louis Post-Dispatch* 19 Apr 1996:A1. For an early article on the role of the media, see: Gunby P. Media-abetted liver transplants raise questions of "equity and decency." *JAMA* 1983;249:1973–82.
  13. For difficulties presented by these types of cases, see: Kluge E-H. Designated organ donation: private choice in social context. *Hastings Center Report* 1989;19:10–6.
  14. Testerman J. Should donors say who gets organs? *St. Petersburg Times* 9 Jan 1994:A1. Compare the case of a Palestinian family who donated their 9-year-old son's organs, after he was killed by a rubber-coated bullet in a West Bank protest, to needy candidates explicitly without regard to national origin or religion; Parents donate organs of son who was shot by Israeli soldier. *Buffalo News* 16 Nov 1997:A11.
  15. In contrast, the law in the state of Louisiana recently was amended to explicitly allow directed donation, and it also requires that organs procured there to be given to recipients in the state unless the OPO cannot find a suitable in-state recipient, in which case organs can be sent to an out-of-state OPO with a reciprocal sharing arrangement (La. R.S. 17:2353, 1999); these laws seem to conflict with the DHHS' final rule mandating broader sharing of organs and accordingly several states requested injunctions against enforcement of the rule (see note 7). See also: Walters J. Whose organs are they? (legal battle over rights to donated organs). *Saturday Evening Post* 1998;270:70.
  16. See note 13, Kluge 1989:10.
  17. On the embeddedness of meaning in consumption and production of goods, see: Douglas M, Isherwood B. *The World of Goods*, rev. ed. London: Routledge, 1996. An extensive literature exists on the concept and related sociocultural dimensions of the body as property, which I do not explore here; in bioethics, see, for example: ten Have H, Welie J, eds. *Ownership of the Human Body: Philosophical Considerations on the Use of the Human Body and Its Parts in Healthcare*.

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18. Head JG, Shoup CS. Public goods, private goods, and ambiguous goods. *Economic Journal* 1969;79:567-72. Cf. von Schubert H. Donated blood—gift or commodity? some economic and ethical considerations on voluntary vs. commercial donation of blood. *Social Science and Medicine* 1994;39:201-6, where it is argued that donated blood should be viewed as a “public good.”
  19. On this debate, see, for example: Hansman H. The economics and ethics of markets for human organs. *Journal of Health Politics, Policy, and Law* 1989;14:57-86; Peters D. A unified approach to organ donor recruitment, organ procurement, and distribution. *Journal of Law and Health* 1989;3:157-87; Barnett AH, Kaserman DL. The shortage of organs for transplantation: exploring the alternatives. *Issues in Law and Medicine* 1993;9:117-37.
  20. Note that Kluge might also extend his argument to address directed blood donation and likely would allow donation within families, given that he does explicitly allow directed organ donation to a family member. On arguments for and against directed blood donation, see: Page PL. Controversies in transfusion medicine: directed blood donations (con). *Transfusion* 1989;29:65-8; Goldfinger D. Directed blood donations (pro). *Transfusion* 1989;29:70-4; Mayer K. The community: still the best source of blood. *Hastings Center Report* 1987;17:5-7; Goldfinger D. The case for directed blood donation. *Hastings Center Report* 1987;17:7-8; Reiss RF, Pindyck J. Reconciling patient wishes with public good. *Hastings Center Report* 1987;17:9-11. In the case of bone marrow donation, although there are often vigorous media campaigns on behalf of a particular waiting individual who has been unable to find an appropriate match within his or her family, volunteers typically have their typing information and willingness to donate recorded in a registry for future use, which could be claimed to negate most adverse effects of what began initially as a case of directed donation. Similarly, oftentimes not all blood designated for a particular recipient is used for his or her treatment and instead is redirected to other recipients in need.
  21. For the most up-to-date report that shows roughly the same discrepancy, see: Department of Health and Human Services, Office of Inspector General. *Racial and Geographic Disparity in the Distribution of Organs for Transplantation*. Boston: Department of Health and Human Services, 1998.
  22. Arnason WB. Directed donation: the relevance of race. *Hastings Center Report* 1991;21:13-9, 16. In the case of a tie based on medical criteria between a Black and a non-Black candidate, priority would be given to the Black candidate.
  23. For a recent discussion of the continued barriers to organ donation and potential methods for increasing consent rates, see: Siminoff LA, Arnold RM. Increasing organ donation in the African-American community: altruism in the face of an untrustworthy system. *Annals of Internal Medicine* 1999;130:607-9.
  24. For a literature review and discussion of factors involved in emotionally related donation, see, for example: Majeske RA, Parker LS, Frader J. In search of an ethical framework for consideration of decisions regarding live donation. In: B Spielman, ed. *Organ and Tissue Donation: Ethical, Legal, and Policy Issues*. Carbondale: Southern Illinois University Press, 1996:89-101. For a recent case that tests the limits of criteria for establishing relatedness occurred with families who met in the hospital waiting room, where one eventually directed donation of a family member’s heart to a member of the other’s family, see: Gilbert K. Hospital friendship and the gift of life. *Baltimore Sun* 10 Mar 1998;B1.
  25. Sade RM. Cadaveric organ donation: rethinking donor motivation. *Archives of Internal Medicine* 1999;159:438-42.
  26. Rorty R. Postmodernist bourgeois liberalism. *Journal of Philosophy* 1983;80:583-9, 583.
  27. Korzick KA, Terry PB. Cadaveric organ donation: rethinking SPRT. *Archives of Internal Medicine* 1999;159:427-8.
  28. Dworkin R. *Taking Rights Seriously*. London: Duckworth, 1977: 233-8. See also: Dworkin R. Liberalism. In: Hampshire S, ed. *Public and Private Morality*. London/New York: Cambridge University Press, 1978:113-43. Notice that by adopting this form of utilitarianism, I explicitly am rejecting forms of utilitarianism that do not assume a minimal amount of egalitarianism, and in turn reject what is commonly termed the “repugnant conclusion” (as coined by J. J. S.

- Smart; e.g., see his contribution to *Utilitarianism: For and Against*. London/New York: Cambridge University Press, 1973). Furthermore, as Madison Powers has put it (Repugnant desires and the two-tier conception of utility. *Utilitas* 1994;6:171-6), it is clearly not the case that all other-regarding (external) preferences are morally repugnant or that all repugnant preferences are external preferences. My main focus here is on external preferences that can be determined to be repugnant because they rely on theories that are contrary to a form of utilitarianism that has equality at its core and that can be affected by policy (i.e., that public policy can be used to establish criteria to eliminate expression of such repugnant or morally suspect preferences).
29. Dworkin's utilitarianism is not the only form of argument that could be used against arguments in favor of directed donation, but it is used here because it is a prominent instance of a theory of utilitarianism that incorporates consideration of preferences; for instance, a relational conception of persons might be developed that could produce a similar taxonomy of permissible and impermissible instances of directed donation.
  30. See note 24.
  31. See note 28, Dworkin 1977:235.
  32. Sunstein C. Preferences and politics. *Philosophy and Public Affairs* 1991;20:3-34, 5.
  33. See note 28, Dworkin 1977:236.
  34. United Network of Organ Sharing. *The Feasibility of Allocating Organs on the Basis of a Single National List*. Richmond, Va.: UNOS, 1991.
  35. See note 34, UNOS 1991:33, n. 2.
  36. For these data, see Gallup Organization, Inc. *The American Public's Attitudes Toward Organ Donation and Transplantation: A Survey*. Boston: Partnership for Organ Donation, 1993.
  37. A recent report from the IOM of the National Academy of Sciences indicates the need to allocate available transplantable organs across wider geographic areas made up of larger numbers of people to enhance the prospects that organs will be allocated to patients with the most urgent medical needs: Committee on Organ Procurement and Transplantation Policy, Institute of Medicine. *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule*. Washington, D.C.: IOM, 1999. See also notes 7, 15.
  38. For a discussion on this issue in the context of candidate selection, see: Ankeny RA. Transforming objectivity to promote equity in transplant candidate selection. *Theoretical Medicine* 1996;17:45-59; see also the special section of *Cambridge Quarterly of Healthcare Ethics* entitled Shaping policy and keeping public trust. 1999;8:269-350.
  39. See note 3, Elster 1983:36.