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Organ Wars: The Battle for Body Parts

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## ARTICLES AND COMMENTARIES: CULTURAL PERSPECTIVES ON ORGAN TRANSPLANTATION

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### Organ Wars: The Battle for Body Parts

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*Transplantation surgeries contribute to conceptions of the body as a collection of replaceable parts and of the self as distinct from all but its neural locus. There remains substantial cultural resistance to these conceptions, which leads the medical community to attempt to link the surgeries to social values that are sufficiently powerful to minimize the sense of a disjuncture between traditional concepts of personhood and those consistent with transplantation. The controversy over how to increase the supply of transplantable organs reveals two diametrically opposed sets of values invoked by advocates of transplantation: altruism and individual rights. The article analyzes these as the ideological equivalents of immunosuppressant drugs, designed to inhibit cultural rejection of transplantation and its view of the body. [biomedicine, transplantation, organ donation, United States, ethics]*

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The powerful antirejection drug cyclosporine became the immunosuppressant of choice for organ transplantation in the early 1980s. Used in combination with corticosteroids, cyclosporine has permitted physicians to delay the body's natural campaign against foreign tissue without simultaneously causing life-threatening side effects.<sup>1</sup> The impact on survival statistics was immediate and impressive, especially for heart and liver transplants.<sup>2</sup> With longer survival times came dramatic increases in the numbers of transplants performed.<sup>3</sup> For example, in 1982, the year before the Federal Drug Administration approved cyclosporine, 103 heart transplants were attempted in the United States. There were 346 such surgeries in 1984, and by 1988 the annual figure had risen to 1,647 (Wolcott 1990:92).

The realities of rejection had always been the ultimate constraint on transplantation surgeries, but with the advent of cyclosporine this barrier was partially

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removed. Medical costs and the availability of donor organs, which were additional constraints on the expansion of transplantation from the beginning, now became the primary factors limiting the growth of the surgeries. The expense of transplantations, as much as \$319,000 for hospitalization alone in the case of liver surgery (Williams et al. 1987) has stimulated passionate argument among politicians and the public alike.<sup>4</sup> Equally intense has been the debate about how to increase the supply of transplantable hearts, livers, kidneys, lungs, and so on. At one extreme are those who view donation as gift giving and who search for ways to encourage altruism (e.g., Hazony 1993; Prottas 1983); at the other extreme are those who urge the development of a futures market in body parts (e.g., Blumstein 1993; Schwindt and Vining 1986).

A self-styled middle ground between these procurement strategies is represented by those who propose "presumed consent" or "routine removal" legislation, donor family compensation plans, or "rewarded gifting" alternatives to donation (e.g., Daar 1991, 1992; Matas et al. 1985; Peters 1991). Presumed consent laws, presently on the books in more than 17 countries (e.g., France, Sweden, Greece, Israel), permit physicians to take organs from a patient after determination of brain death unless there is a known objection from either the deceased or the next of kin. Routine removal laws would do the same, but only after relatives are given the right of "informed refusal" (Matas et al. 1985).<sup>5</sup> In a restricted sense "rewarded gifting" refers to cash payments given to living kidney donors, but the term might just as well apply to other proposed financial compensations given to next of kin who agree to donate their relatives' organs (e.g., a preestablished "death benefit," payment of funeral expenses, donations to a charity of the family's choice). Proponents insist that this kind of compensation preserves the ethic of altruism while also providing some of the incentive claimed for a more explicit market approach to organ procurement.

The shortage of organs for transplantation and the controversy over procurement strategies provide the focus for this article. They signal an ongoing cultural dispute over the meaning of the body as its parts acquire utility beyond their natural anatomical functions. Together with numerous other innovations in biotechnology (e.g., Jaffee 1990; Kimbrell 1993; Rabinow 1992), transplantation challenges traditional assumptions of self/body integrity by promoting a distinction between the brain as the center of consciousness and all other organs as replaceable parts (Fox and Swazey 1992; Lock and Honde 1990; Ohnuki-Tierney 1994).<sup>6</sup> However, this view of the body and its correlated notions of personhood have not been embraced without resistance in either the United States or in other countries.

In this article I review the evidence of this resistance first at the level of individual responses and then in terms of broader sociocultural reactions to organ transplantation. I suggest that just as the biological process of rejection must be suppressed for transplantation to succeed, so must there be an ideological equivalent to cyclosporine to inhibit the cultural rejection of the surgery and the view of the body it promotes. The arguments about organ procurement reveal a continuing debate within the transplantation community about which ideological alternative, gift-giving or property rights, will serve best as a "cultural suppressant" (without harmful side effects).

## Cellular and Psychological Rejection

The biochemical process of rejection is conceived in immunology texts and popular press alike (Haraway 1993; Martin 1990, 1994) as a kind of organic warfare between “self” and “nonself” in which the phagocytes, “helper” and “killer” T cells, and B cells of the immune system identify and destroy foreign substances. In the case of organ transplantation, even careful blood and tissue matching between donor and recipient only reduces the likelihood of the immune system’s treating the introduced tissue in the same manner as viruses.<sup>7</sup> Unless suppressed by powerful drugs such as cyclosporine, the immune system eventually mounts an attack on material that it considers dangerous to the survival of the entire system.

The crucial clinical point about rejection for transplantation is that the body never accommodates the presence of foreign tissue. The moment the immune system is released from its pharmacologically induced stupor, it immediately initiates an all-out attack on the transplanted organ(s). The boundary between “self” and “nonself” is, from an organic view, nonnegotiable and indelible.<sup>8</sup> Although the dosage and mix of antirejection drugs initiated after surgery may be fine-tuned over the months and years that follow, survival for the transplant recipient is contingent upon the continued suppression of the immune response. It is for this reason that one surgeon characterized transplantation as replacing one fatal disease for others that are at least treatable (e.g., those related to the long-term use of immunosuppressants) (cited in Gutkind 1988:342).

A number of physicians and researchers have noted an interesting parallel between the immune system’s rejection of foreign tissue and the psychological rejection experienced by at least some transplant recipients when they try to adjust to the fact that they have other people’s organs in their bodies. It is not uncommon for recipients to experience difficulty “incorporating” the new organ into their self-image (Bourgeois et al. 1990; Castelnuovo-Tedesco 1973, 1978; Dubovsky et al. 1971; Fox and Swazey 1974:27–32; Fricchione 1989; Kuhn et al. 1988:111; Sharp 1995; Simmons et al. 1979:67–68), and there are many cases in which the characteristics of the donor (e.g., sex, age, race) are thought to have been transplanted along with the organ (Basch 1973; Brochier et al. 1990; Bunzel et al. 1992; Gutkind 1988:185; Houser et al. 1992:41; Mai 1986:1160; Rauch and Kneen 1989:48). Some transplant specialists would go so far as to argue that psychological and physiological rejections are linked, although the direction of any cause and effect relation remains unclear (Fricchione 1989:411; Rauch and Kneen 1989:54).

Rejection at the psychological level is thought by most to differ from immune-based rejection in that, unlike the latter, it seems to be only a temporary response. Psychiatrists and social workers describe adjustment stages in which the transplant recipient progressively normalizes the experience of a foreign organ and comes to think and feel about it as any other body part (Kuhn et al. 1988:112; Muslin 1971; Rauch and Kneen 1989).<sup>9</sup> According to some, this adjustment can come very quickly, even within the first weeks after surgery (Fricchione 1989). There are intriguing suggestions in the literature that some organs may be emotionally integrated more easily than others, with the heart often cited as the most difficult case due to its symbolic associations (Castelnuovo-Tedesco 1973:357; Keyes 1991:167; Norvell et al. 1987:27).

Whatever degree of psychological accommodation is achieved by transplant recipients in integrating the new organ into their self-image, it is unlikely that it represents the emotional triumph some would make it out to be. It is not just whether the donor is somehow present in his or her organ that challenges the recipient's ability to adjust psychologically to the surgery, nor even the continuing experience of indebtedness to the donor captured by Fox and Swazey's notion of the "tyranny of the gift" (1978:383). Also at issue is the awareness of being surgically reconstituted and permanently at risk of rejection. The impressive surgical scar (especially for heart and heart/lung transplants) physically inscribes the fact of transplantation, while the strict schedule of medications and regular clinic visits for sometimes invasive tests serve as recurrent reminders of potential rejection. Carol, a New Mexico heart recipient "ten years out," described her daily routine in a manner that conveys the continuous caution she experiences:<sup>10</sup>

Well, it is a part of my daily awareness in as far as I have to take medication four times a day, and I've often said, if I could have one wish it would be to have one day without having to take pills.

*Q:* How many pills altogether per day do you take?

*Carol:* Uh, probably 27, and it's strung out over about six different times.

*Q:* And you have to keep that schedule?

*Carol:* Yeah. . . . One of the pills, the major antirejection drug, the cyclosporine, you have to take 12 hours apart. . . . And boy they drill you and grill you before you leave that if you forget it, you know, you're really causing yourself major trouble, and so that one I get real nervous about. Sometimes I can handle being off the mark by 15 or 20 minutes and other times I'm watching the clock the whole time.

Don, another heart recipient from New Mexico, has had two years of impressive health since his surgery, but a recent test indicated vascular rejection. He commented on his posttransplant life:

So I think it's an ongoing, not a battle, but an ongoing thing that you've got to be conscious of. You aren't, you are not normal. Although I feel normal and everything, and I'm as normal as anybody can be, I think, but you really aren't. You sometimes try to fool yourself, like you try to go back to a normal diet. You can't. I mean, that reflects on my blood work [finger snap] right away.

The transplantation community itself contributes to the recipient's continuing awareness of being "not normal" and "at risk." It promotes ties between patients through support groups that focus on postsurgery complications and rehabilitation, but that also have the effect of forming social bonds, and sometimes important friendships, based on the shared identity of "transplant."<sup>11</sup> Transplant coordinators also ask recipients to give public presentations on the importance of organ donation and to counsel individuals who are deciding whether or not to pursue surgery or who are still waiting for an organ to become available. Finally, through magazines sponsored by drug companies (e.g., *Encore* and *Lifetimes*), newsletters from the National Kidney Foundation, and even an biennial athletic competition, the Transplantation Games, the broader transplantation community gives recipients few opportunities to escape awareness of their special status.

Neither the relative routinization of life after hospitalization nor the explicit efforts of psychiatrists and surgeons to convey a purely mechanistic view of body

parts (e.g., patients must grasp “that hearts are merely muscles that have little to do with self” [Rauch and Kneen 1989:53]) obliterate the graft recipients’ consciousness that their transplant identity is a compound of “self” and “other.”<sup>12</sup> They are always just a thought away from the recognition that only a temporary truce keeps them from an organic war with the “other” in their body. This awareness is as indelible as the genetic foundation on which it rests.

### Cultural Rejection?

In his article “Harvesting the Dead,” Willard Gaylin (1974) imagined a not-so-distant future in which thousands of brain-dead bodies (“neomorts”) would be maintained in “bioemporiums” for medical students to practice physical exams on, for researchers to use in experiments on drug toxicity, for the therapeutic collection of regenerative fluids and tissue (blood, bone marrow, semen, ova, etc.), and for removal of organs as needed (see also Jonas 1974). After advancing the advantages for the greater good, Gaylin asked, “Where in this debit-credit ledger of limbs and livers and kidneys and costs are we to weigh and enter the repugnance generated by the entire philanthropic endeavor?” (1974:30).

In 1978 the California Department of Transportation acquired, with consent from next of kin, a number of human cadavers to use in automobile crash tests designed to compare different air bag systems. The bodies would reveal more about traumatic injuries than the dummies available at the time, and so their use was also justified by a utilitarian calculus of the greatest good for the greatest number. State Congressman Moss was not persuaded: “The use of human cadavers for vehicle safety research violates fundamental notions of morality and human dignity, and must therefore permanently be stopped” (quoted in Feinberg 1985:31).

In 1983 Virginia physician H. Barry Jacobs, whose medical license had been revoked for fraud (Hazony 1993:225), founded International Kidney Exchange, Inc., with the goal of brokering the sale of kidneys from live donors in the Third World (or from impoverished Americans) to patients in need of transplants who could afford the market price. The outrage his proposal produced contributed to the prohibition against the sale of organs in the National Organ Transplantation Act (1984, Public Law 98-507). By 1989 similar statutes criminalizing the sale of human organs had been passed in 20 countries (Fox and Swazey 1992:66).

These three examples are drawn from the front lines of an ideological war over the meaning of the human body in which organ transplantation is a major battlefield.<sup>13</sup> The conflict emerges from the unresolved tension between two Western views: “The body as a mere thing carried by a triumphant science and technology, and the still present sense that the body and its parts are always more than things . . . that the ‘person’ is inextricably tied to the sheer materiality of the body or its parts” (Rabinow 1992:185).

More than a decade ago, Russell Scott, then head of the Australian and New South Wales Law Reform Commissions, addressed the significance of organ transplantation for our view of the body. He asked whether “the revulsion we feel upon learning of the technical practicality of these activities arises from our essentially human characteristics, which we could not eliminate without diminishing our humanity, or from our current moral attitudes and training, and fear of new technology” (Scott 1981:165). His answer: if, after the shock of a pioneering

medical advance wears off, sufficient benefit is found to result, then society adjusts by shifting its values (1981:80). As regards organ transplantation from cadavers, Scott insisted that “[w]e are dealing with deep-rooted attitudes and nothing more, attitudes which are in fact changing” (1981:260).

It is useful, I think, to return to the analogy of rejection to judge whether Scott’s prediction is correct. The “revulsion” to which he referred, like Gaylin’s “repugnance” and Congressman Moss’s moral outrage, ultimately traces back to the same question of the definition and boundaries of the “self” to which our immune system responds so unambiguously in the biological processes of rejection. Rephrasing Scott’s question accordingly: Are the efforts to reconceptualize the body as distinct from the person inhabiting it like cyclosporine for the social conscience, suppressing but never eliminating a cultural insistence on self/body inviolability? Or are such efforts destined to accomplish at the cultural level that which our biological responses prohibit, a permanent reconstruction of the self in a manner that separates identity from its corporeality and permits a blurring of the boundary between self and other? In short, are we witnessing a cultural equivalent to immune-based rejection to transplantation, or is this cultural accommodation in process?

### Evidence of Cultural Rejection

From the earliest years of transplantation surgery, physicians have treated these cultural dimensions as essentially nonproblematic. Most, like Scott, have assumed that society would accept the authority of medical science and make the changes necessary in conceptions of death and personhood for transplantation to progress. For example, when the Harvard Brain Death Committee met from January to August 1968, it assumed that redefining death was merely a technical exercise required by improvements in life-support technology (see Rothman 1991:161–165). The committee’s report, published in the *Journal of the American Medical Association* the same year, justified the new criterion for death—no cerebral or brain stem activity—by citing the need for standards by which to determine when resuscitative and support care should be terminated. However, few doubt that the priority of harvesting healthy organs for transplantation was as important a motivation in the proposed change as establishing standards for terminating care for patients in irreversible comas.<sup>14</sup>

As certain as the Harvard committee may have been that social consensus would quickly follow their proposal, the response was anything but receptive. Rothman (1991:163–164) documents the negative reaction of the U.S. public as made evident in a proliferation of popular press articles that followed publication of the committee’s report. Today, some 26 years later, there is ample proof that a redefinition of death based on brain activity is still the subject of significant cultural ambivalence. Intensive care nurses testify to the difficulty of explaining to relatives why the heart-beating, normal-colored, apparently sleeping patient is actually dead (Helmberger 1992:171–178; Perkins 1987:925; Revkin 1988; Youngner et al. 1985). Research in minority communities on attitudes toward organ donation reveals widespread suspicion that brain death might be declared prematurely to provide access to organs for transplant (Callender 1987:1551); it also cites notions of death in “religion, myth, and superstition” (read: culture) that can lead to donation refusals (Perez et al. 1988:556). Even those one might expect to have long

ago embraced the new definition—namely, physicians and nurses—demonstrate substantial philosophical confusion about the concept of brain death and a wide range of personal views about when life ends (McGough and Chopek 1990; Youngner et al. 1989).

Transplantation organizations similarly assumed that once educated about the life-saving qualities of the surgery, the public at large would be quick to sign donor cards and to respond favorably to donation requests upon the death of kin. Yet despite massive publicity campaigns and educational efforts, the rate of donation leveled off around 1987 at 4,000 per year (Hazony 1993; Peters 1991). The most recent figure of 4,860 for 1993 (source: United Network for Organ Sharing) indicates that promotion has not kept pace with growth of the waiting list, currently at 33,000 (source: National Kidney Foundation). Despite the fact that the United States has the largest organ procurement system in the world, only 15 percent of those who die in a manner that would permit donation actually have their organs harvested (Hazony 1993:219–220).<sup>15</sup> In one carefully designed study, pronounced differences were found by both ethnic and geographic variables for rates of family refusals to donate the organs of deceased kin. The rates ranged from 11 percent for whites in Miami to 55 percent for African Americans in New York City (Perez et al. 1988).

An additional indication of continuing cultural resistance to the idea of transplantation comes from public opinion polls on attitudes to donation. While advocates are quick to cite the impressive level of general approval of organ donation, as high as 90 percent in one poll (cited in Annas 1988:621), the research has consistently shown a significant decline in support as questions shift from abstract approval of transplantation to concrete circumstances of donation (Maninen and Evans 1985; Miles and Frauman 1988; Prottas 1983:283). In addition, high rates of nonresponses to the pollster's questions (e.g., "don't know" or "no answer") are often not sufficiently emphasized. In a North Carolina telephone survey, for example, 15–19 percent of the 585 respondents refused to answer questions about organ donation (Miles and Frauman 1988:76). In a national telephone survey with 2,056 respondents, between 38 percent and 43 percent "did not know" whether or not they would be willing to donate specific organs (Maninen and Evans 1985:3114). A reasonable interpretation of all this survey evidence is that Americans have not fully embraced organ transplantation and/or the views of the body and death it requires.

Broadening the scope to the international arena, there is still more impressive evidence of cultural resistance to transplantation. The proliferation of sensational stories of black markets in organs (e.g., Chengappa 1990; *Economist* 1994; Hedges 1991; see also Fox and Swazey 1992:66; Sells 1990) points to cross-cultural suspicions that transplantation may stimulate unacceptable violations of human rights. The stories may well have contributed to the rash of charges that Americans are traveling abroad in search of babies for body parts (e.g., Pulin 1994). In Guatemala, centuries-old beliefs that foreigners steal children for utilitarian ends (Adams 1955:448–450) merged with stories of Americans taking babies for their organs. One result was the savage beating on March 29, 1993, of June Weinstock, an Alaskan environmentalist accused by an angry crowd of stealing a child during a visit to San Cristobal.

A less dramatic illustration of how transplantation is interpreted and partially rejected on the basis of preexisting cultural frameworks comes from Japan. Despite widespread publicity and debate, there remains substantial opposition to a definition of death based on brain activity and to a purely biomedical understanding of body organs (Feldman 1988; Lock and Honde 1990; Ohnuki-Tierney 1994). The research in Japan represents the first serious attempt to explore the cultural construction of transplantation anthropologically. Like the tantalizing evidence from other countries cited above, it confirms that this surgery raises such serious cultural issues as to question Scott's optimistic prediction that transplantation eventually will be fully accepted.

### Antirejection Ideologies

The previous section showed that the conceptions of death and the body that accompany transplantation still face substantial cultural resistance both nationally and internationally. The cultural boundaries of the self (in time and in relation to others) are no more easily violated than are the biological bounds enforced by the immune system. What are the cultural equivalents of cyclosporine with which proponents of transplantation seek to suppress and/or permanently defuse this resistance? The answer is most clearly framed by the ideological battle over organ procurement, since it is here that transplantation is promoted to the public as a whole.

Two culturally potent scripts, gift giving and property rights, have been invoked in the United States as ideological supports for organ donation.<sup>16</sup> In both cases transplantation advocates make use of the culturally familiar to legitimize what is in fact a profound transformation in the way we think about and act toward the human body. In what amounts to a "cultural transplantation," clusters of powerful images and priorities are taken from other domains of social and economic life and grafted onto the idea of organ transplantation so as to make it seem to be fully consistent with those cultural meanings. In some cases this is a deliberate and intentional effort, while in others the authors appear to be far less conscious of the cultural linkages on which their arguments depend.

Although these two ideologies are in opposition to one another, they begin from a common cultural baseline. Each draws upon the peculiarly American theme of a triumphant medical science challenging death, of men in white coats (the majority of surgeons are still male) facing down the Grim Reaper (Fox and Swazey 1992:199). By associating transplantation with the genre of "modern medical miracle stories," they sidestep the bundle of economic issues that might otherwise challenge the surgeries on grounds of health care equity.<sup>17</sup> The blizzard of media stories that accompanied early transplantations (e.g., Christiaan Barnard's first heart transplant in 1967), as well as the continuing supply of poignant reports of innocent lives saved by heroic surgeries (e.g., a *20/20* segment on January 28, 1994), provide cover for both sides to define the problem as a shortage of donors, not dollars. As Senator Orrin Hatch observed in opening Senate hearings on organ transplantation in 1983, anyone who questions this medical marvel "would quickly earn the title of 'Scrooge of the Year'" (cited in Schwartz 1985:402).

Casting transplantation as an unquestioned good permits proponents of both positions to declare a moral crisis, a tragic shortage of organs that condemns

thousands to die while waiting for an organ to become available. In what has become a formulaic presentation, essays begin with statistics from the United Network for Organ Sharing (UNOS) that show ever-increasing numbers of potential recipients who die before an organ is made available (e.g., Bailey 1990:370). This is commonly followed by the arguments, again with statistical support, that the shortage is unnecessary (and therefore even more tragic) because there are sufficient numbers of persons dying each year in ways that would permit their organs to be reused (i.e., trauma to the head with little or no other injury to the rest of the body), and because there is substantial public approval of donation (citing poll data).

### *The Gift Ideology*

At this point the arguments typically separate, each proposing different solutions to the shortage and, in the process, calling forth diametrically opposed cultural priorities. To conceive of transplants as gifts is the orthodox position; the idea has been central to the way the surgery has been presented to the public since its earliest days (Fox and Swazey 1974).<sup>18</sup> For example, the first federal legislative act to address the question of harvesting organs was titled the Uniform Anatomical *Gift Act* (1968, emphasis added). References to the “gift of life” found repeatedly in both medical and popular accounts of transplants, not to mention the connotations that accompany the terms “donor” and “recipient,” link the medical procedures to complex notions of generosity, altruism, and selflessness.

These foundational values are given religious sanction when proponents of donation call upon religious authorities to declare their approval of transplantation. The views of theologians from Christian, Islamic, Hindu, Jewish, and Buddhist traditions have been solicited (Keyes 1991:181–224; Hawke et al. 1990:84), leading to the conclusion that “most religious leaders worldwide consider organ and tissue donation the ultimate charitable act” (National Kidney Foundation, Fact Sheet for the 1994 U.S. Transplant Games). We will see below that advocates of the property rights ideology contest the claim that moral authority applies only to donation.

The gift ideology is given its most dramatic presentation during the Transplant Games. Begun in 1982, this athletic competition for transplant recipients is simultaneously a celebration of the “triumph of transplantation” and an impressive public relations effort to encourage organ donation. The 1994 Games in Atlanta, Georgia, on August 3–7, attracted 1,050 participants of all ages and ethnicities from across the country. They wore t-shirts with messages such as “Recycle Yourself” and “Sign Up For Life” (i.e., sign donor cards); ribbons pinned to their shirts recognized the donors whose organ(s) they received, teal colored for living donors and salmon colored for deceased donors. Speaker after speaker at the opening ceremony referred to the “second chance at life” made possible by the generosity of donors. They encouraged the public to “share your life and share your decision.” Representatives of donor families were given flowers in gratitude as a 24-year-old heart transplant recipient sang his own sentimental composition, “The Gift of Life.”

In an intentionally provocative recent article, Ohnuki-Tierney argues that the gift metaphor is a dangerous mystification of transplantation in that it cloaks a “transaction completely devoid of social relationships” in the appealing disguise

of exchange and interdependence (1994:241).<sup>19</sup> Her critique aims in the right direction, but it requires several qualifications. First, the earliest successful transplants, from which the gift metaphor emerged, were kidneys donated by close living relatives. These were clearly embedded in the nexus of intimate family relationships, and the fact that by definition they are “unrepayable” (Fox and Swazey 1992:40) actually intensifies and complicates the social ties involved (Basch 1973; Murray 1987a:33; Simmons et al. 1979:153–197). Second, one need only listen to the recipients of organs from cadaver donors to realize that the medical establishment’s efforts to desocialize the relationship between donor and recipient are not entirely successful (Helmberger 1992; Sharp 1995). Immediately after Sylvia, a liver transplant recipient, declared that she had always thought of the organ as hers (“I paid x amount of dollars for it”), she proceeded to refer to the donor as “an angel on [her] shoulder” to whom she gives thanks “for every day of [her] life.” Recipients and/or their families often write emotional letters of gratitude to donors’ relatives; transplantation counselors serve as intermediaries in these exchanges to assure donor confidentiality, but it is not unusual for the letters to be answered and even for subsequent visits to be arranged. To illustrate, Gutkind (1988:356–359) describes the emotional scene when the father of a young male donor put his ear to the recipient’s chest to listen to his son’s heart beating.

Finally, in the case of cadaver donation, the association being promoted is not to the direct reciprocal exchange that cements individual and group ties, but to that cluster of selfless acts that affirm a more diffuse solidarity (Murray 1987a, 1987b). Proponents of the gift ideology seek to connect organ donation to the sorts of acts Americans perform during disasters and accidents: caring responses to personal tragedies even when the individuals affected are strangers and there is no expectation of repayment. The generosity of strangers, the heroism of the person who risks life and limb to rescue those he or she does not know, the coming together of neighborhoods in mutual support at moments of natural destruction: these are the cultural ideals with which advocates of the organ-as-gift ideology wish to associate donation (see also Titmuss 1972). By giving organs we contribute to “*communitas*” (Turner 1969).

### *The Property Rights Ideology*

Well before the infamous Dr. Jacobs tried to set up a kidney brokering firm, predictions were made that a shortage of donors would eventually force the application of market principles of supply and demand to organ procurement (e.g., Dukeminier 1970). In the 1980s and early 1990s there has been a proliferation of articles, usually appearing in law reviews and law and economics journals, advocating the commercialization of body organs.<sup>20</sup> Most adopt a libertarian view of the individual’s right to enter into contracts that treat the body and its parts as disposable property. All agree that the present altruism-based system will never provide sufficient numbers of organs given current and future demand; some kind of financial incentive is required.<sup>21</sup>

The cultural priorities invoked by these writers are individual autonomy, rational self-interest, and freedom from onerous state controls. Their case also rests on a faith in the efficiency of markets to provide incentives that balance supply and demand; this faith grants markets an almost mystical power to resolve human

problems, including moral dilemmas. According to the gift ideology, the donor is the selfless citizen offering organs to strangers; the vision of property rights advocates is of the entrepreneur allocating resources according to rational calculations of costs and benefits. It's the Good Samaritan versus Horatio Alger.

Proponents of the property rights ideology recognize—even revel in—the fact that their proposals often meet with repugnance and condemnation.<sup>22</sup> They see themselves as representing reason and rigorous analysis against “shibboleth and shamanism” (Blumstein 1993:3), a crucial “first step toward a more rational public policy” (Kaserman and Barnett 1991:57). Their proposals may seem to be “the ravings of ghoulish law and economics fanatic[s]” (Cohen 1989:51), but, they insist, they occupy the moral high ground by favoring the living over the dead. It is, after all, “hardly an act of great generosity to donate that which you cannot use and may not sell” (Cohen 1989:28); “to cling to an ideal which condemns some people to death or suffering is a high price to pay for idealism” (Brams 1977:195).

Setting aside the rhetorical flourishes with which these authors make their case, significant cultural issues related to notions of personhood are raised by their claim that bodily organs are no different from other “necessary commodities” (Chapman 1983:405). This central contention relates to the notion of “ownership” as it applies to the corporeal part of the person. Legal scholars have noted that the courts and public opinion have come a long way toward recognizing property rights and commercial value in some of what the body produces during life, for example, blood, hair, semen, ova (Andrews 1986; Dickens 1991; Jaffee 1990; Radin 1987). Similarly, common law and recent legislative efforts (e.g., authorizing donor cards) affirm at least a “quasi-property” right in corpses (Andrews 1986:29; Jaffee 1990:543–544). A corpse has always been considered the property of the next of kin to the degree that he or she has the right and obligation to claim it for decent burial in a condition as undisturbed as the circumstances of death permit. Under the Uniform Anatomical Gift Act, the deceased is granted continuing rights in his or her body to the extent that an advanced declaration of a wish to donate is legally enforceable.

Thus, some of the “twigs” in the legal bundle of property rights (Jaffee 1990:548) are already extended to the body and, for at least some bodily tissues and fluids, all of the rights associated with property apply (e.g., the right to sell). Why, ask market proponents, shouldn't we travel the final distance and permit individuals full property rights in the entire body? After all, they argue, the prohibition against the acquisition, receipt, or transfer of human organs “for valuable consideration” (National Organ Transplantation Act) does not stop hospitals, medical staff, pharmaceutical companies, and so on, from earning profits on donated organs. The only party denied profit is the “owner” of the property (Andrews 1986; Daar 1992:2209; Mavrodes 1980:137).

Margaret Radin, legal scholar and expert on property rights, critiques this view of the body as a commodity by highlighting the threat it poses to commonsense notions of personhood:

In our understanding of personhood we are committed to an ideal of individual uniqueness that does not cohere with the idea that each person's attributes are fungible, that they have a monetary equivalent, and that they can be traded off against those of other people. Universal market rhetoric transforms our world of

concrete persons, whose uniqueness and individuality is expressed in specific personal attributes, into a world of disembodied, fungible, attribute-less entities possessing a wealth of alienable, severable "objects." [1987:1885]

Radin acknowledges the degree of commodification to which the body and its parts have already been subjected, but insists that this does not obligate us to pursue the market analogy to its logical end. We can, and should, live with an "incomplete commodification" that preserves as inalienable those things "important to personhood" (Radin 1987:1937). This, of course, begs the question of why some bodily tissues and fluids should be considered less important to personhood than others, and therefore commodifiable. On what cultural basis can this differential treatment of "body parts" be justified? Also left unanswered by Radin's characterization of our view of personhood is whether or not death releases previously inalienable "attributes" for post mortem commodification.<sup>23</sup>

As important as any direct effect the market ideology may have on traditional notions of personhood is the political space it has opened for positions that become, by contrast, moderate alternatives. Market proposals that prompted outrage and congressional action in the early 1980s are now appearing routinely in academic journals and even popular magazines and newspapers (e.g., Bailey 1990; Hitt et al. 1990; Khanna 1992). The context for this change extends well beyond developments in medicine. It includes the general political movement to the right under President Reagan, with its explicit free market rhetoric, and the campaign by law and economics professors (e.g., Richard Posner, Elisabeth Landes) to apply market logic to areas of life previously not commodified (e.g., child adoption, sexuality and reproduction).

As extreme market proposals have gained enough legitimacy to be the subject of debate rather than of dismissal, there has emerged a self-proclaimed middle position that attempts to blend market and gift ideologies. Especially notable, because it comes from within the transplantation community, is the effort of A. S. Daar to justify what he calls "rewarded gifting" or "donation with incentive" for kidney transplants involving nonrelated donors and recipients (Daar 1991, 1992). Daar demonizes more extreme market proposals as "rampant commercialism" and stipulates "features of moderation" (1992:2210) by which his form of compensation could be ethically regulated. He insists that his proposal is consistent with the socially acceptable idea of "incentivising" good acts (1992:2210).

Essentially the same defense is offered by another pioneer of the middle ground, Thomas Peters (1991), who suggests that a regulated "death benefit" of \$1,000 paid to the estate of a donor avoids the ethical pitfalls of crass commercialism while still providing motivation to donate. These and other mixed proposals appear to be gaining ground in medical circles, despite the criticism that they are nothing but markets in disguise (e.g., Abouna et al. 1991:164; Pellegrino 1991). They are also finding expression in the general media (e.g., Young 1994). This success is in no small measure linked to the rhetorical claim of moderation made possible by the expression of far more extreme proposals.

### **Anthropological Reflections**

The ideological battle between "givers" and "sellers" must be kept in perspective because both parties promote a transplantation-inspired view of the person that

is at odds with the dominant cultural model not only in the West, but also cross-culturally. Philosophical debates notwithstanding (see Murray 1987b:1062–1074), one of the most characteristically human activities is the treatment of the dead as though some quality of the “person” is still present. Equally panhuman is the assumption that the self and the body are integral to one another; in fact, in diverse cultures sickness is attributed to the temporary separation of the two (e.g., soul loss). The weight of cultural precedent is clearly on the opposite side of a view of personhood that treats the body as separable from self, whether for the purpose of generous donation or self-interested gain, and whether before or immediately after death.

Exactly which body parts are considered to be integral to personhood is far more variable by culture (Synnott 1993). For example, selling hair may be a legitimate economic venture in America, but in many societies it would subject the individual to the risk of sorcery according to a more inclusive notion of bodily integrity (e.g., voodoo). The present debate in the United States about the marketing of fetal tissue for medical research and drug production is another example of how culturally specific conceptions of the person influence where the boundary is drawn between alienable and inalienable body parts.<sup>24</sup>

It may be that the incremental inclusion of more and more body parts in the category “nonessential to personhood” will have the cumulative effect of straining notions of bodily integrity to the breaking point. This is unlikely to come about solely because of growth in transplantation, since even if the entire need for organ replacement were to be met, only a small fraction of the population in the United States would be directly affected as donors or recipients. For a profound transformation in cultural conceptions of the person to occur, surely a greater critical mass would have to be influenced by the precipitating changes.

The combined effect of many biotechnologies, each challenging particular aspects of self/body attachment, might be sufficient to cause that revolutionary reformulation of our concept of the person (Kimbrell 1993). Perhaps transplanting organs together with genetic engineering, artificial reproduction, therapeutic cell lines, and mechanical implants will be enough to overwhelm the intuitively unambiguous connection we feel to our bodies. But it is also important not to underestimate the cultural force behind the idea that self and cell are not entirely separable, that it is not only the brain in which the “I” resides. After all, as is made clear by even a cursory view of the process of rejection, the intuition of bodily integrity has a solid biological foundation.

This is not to say that transplantation and the ideological battle over procurement are of no consequence to our notions of personhood. What I am arguing is that, at least for the present and near future, the *cultural* success of transplantation will be measured by how effectively its supporting ideology suppresses, rather than replaces, traditional concepts of bodily integrity, including the idea that the social relevance of the body to the self does not evaporate with a declaration of brain death. This is the standard by which to judge the likely outcome of the conflict between gift and property rights’ advocates.

The obvious advantage held by those who would wrap organ donation in the rhetoric of gifts is that this approach appropriates the nonmaterialist conception of the body that underpins traditional views: that is, organs remain meaningfully

connected to self via the act of generous sacrifice. The market ideology can also lay claim to a thread that runs deep in American culture: the value placed on individual autonomy and the freedom to act in perceived self-interest. However, in its more extreme versions, it requires too great a departure from the powerful symbolism of an embodied self to be persuasive. For all their reasoned argument and moral insistence, market advocates will have to accept that most Americans are not prepared to equate their body parts with the property they buy and sell and bequeath in wills.<sup>25</sup>

To conclude, let me return once more to the concept of rejection. As experience with cyclosporine increased, physicians came to discover that they could achieve better graft survival by combining the drug with low-dose steroids (“double therapy”) and another immunosuppressant, azathioprine (“triple therapy”). By analogy, it may be that some combination of supporting ideologies, some blend of gift and market rhetoric and policy, will prove more effective in suppressing the cultural rejection of a disembodied self. The trick, as in drug therapies, will be to blend powerful cultural themes that are not themselves antagonists. It remains to be seen whether there might be such a combined “therapy” in a mix of gift-giving rhetoric and noncommercial compensations to donor families.

## NOTES

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1. The long-term physical damage attributable to cyclosporine became a focus of investigation only after transplant recipients began to survive long enough to study the effects of prolonged use. There is evidence that chronic use of the drug strains the kidneys (Gutkind 1988:64; Randall 1990). Promoters of the new immunosuppressant, FK 506 (tacrolimus), promised less severe side effects, but recent studies suggest that, like cyclosporine, it can cause kidney damage with prolonged use (Wallemacq and Redling 1993).

2. One-year survival rates for heart transplants jumped from 58 percent to 80 percent with the use of cyclosporine; for liver transplants the improvement in one year survival was from 25 percent to 50–70 percent (Blair and Kaserman 1991:409). Recipients of kidney transplants are less vulnerable to mortality from rejection because they can be returned to dialysis should the graft fail. For heart and liver transplants, the only response to rejection is retransplantation, a course associated with much lower survival statistics.

3. Better outcomes contributed to transplantation’s shift from experimental to standard treatment status for a wider array of diseases and for patients of a greater age range. Improved outcomes also resulted in greater acceptance of transplantation coverage by health insurers.

4. There is a significant range in the cost of transplantation. Kidney transplantation can cost as little as \$25,000 for surgery and one year of treatment (Smith 1990:12), and it actually saves money over the alternative of dialysis (Eggers 1988:228). Perhaps the most dramatic example of a public debate about the expense of transplantation comes from Oregon, where the state legislature faced moral condemnation when its health care rationing plan led to the denial of coverage for a bone marrow transplantation for 7-year-old Coby Howard, who subsequently died of acute lymphocytic leukemia (Fox and Swazey 1992:90).

5. In practice, the distinction between presumed consent and routine removal with an option of informed refusal is made less significant by the fact that physicians generally hesitate to proceed without approval from next of kin even when legal statutes permit them to do so.

6. I agree with Renée Fox's (1990:207) contention that biomedical advances alone have not created or caused the sorts of cultural debates with which this article is concerned. She is correct in rejecting a "biomedical and technological determinism" that ignores the many nonmedical factors that also shape our conceptions of self and society.

7. Organ donation between identical twins is the safest transplant strategy exactly because of the absence of immune response when the transplant is a perfect genetic match. The degree of immune response also varies by the organ being transplanted.

8. Martin (1994:108–111) argues that within the field of immunology there are challenges to this self/nonself model, but I find little evidence that alternative conceptions have penetrated into the professional transplantation literature or affected the interpretations of organ recipients.

9. This idea of "stages of adjustment" is similar to many other efforts in medicine to establish a normative, developmental sequence of distinct phases in treatment. While it may facilitate evaluations of "progress," it probably accounts poorly for the reality of a transplant recipient's experience. A roller-coaster metaphor is more in keeping with what recipients actually report (e.g., Helmberger 1992).

10. This and the following quotes from organ recipients derive from five open-ended interviews I carried out in Albuquerque, New Mexico, in November 1993. My objective in this initial study was to explore posttransplant realities with a small group that varied by age, sex, and ethnicity. Interviews, with one exception, were carried out at the individual's home, and consent was given for tape recording.

11. Some support groups are broken down into smaller organizations based on the organ(s) transplanted. I have heard these subgroups referred to as "the hearts" or "the livers," which further indicates the degree to which a transplant identity emerges after surgery.

12. Lesley Sharp's (1995) research has underscored the degree to which the "self" is reconstructed after transplantation.

13. I use the war metaphor here not just to be consistent with the imagery of the immune system, but because of the vehemence of the polemics on both sides. From one direction come dire warnings of an imminent moral Armageddon, while from the opposite are heard promises of emancipation from ignorance and onerous state controls.

14. An early draft of the committee's report explicitly mentioned the condition of organs for transplantation as one of its central concerns (Rothman 1991:162).

15. The statistics regarding donation rates are hotly contested and vary by wide margins because of different definitions of the potential pool of donors. Those who wish to stress the urgency of the "organ shortage" give rates based on total deaths, while those who seek to diminish the sense of crisis compare actual donation rates to the far more restricted number of deaths that medically could produce usable organs (e.g., respirator-dependent, brain-dead). By this latter measure, one analyst suggested that as many as 50–60 percent of potential donors are used (Guttmann 1991:456). I would argue that even this rate indicates substantial cultural resistance.

16. The focus of the following discussion is the United States. However, the conception of organs as gifts is to be found worldwide, in legislation related to transplantation, as well as in promotional materials. The application of property rights arguments to transplantation is largely an American discourse, but attempts to commodify organ donation have been documented in Germany, the Soviet Union, Egypt, India, Pakistan, Argentina, Korea, and Hong Kong (Kimbrell 1993:31–32; Lamb 1990:137; Scott 1981:2).

17. There are, of course, many who do raise this cost issue (e.g., Fox and Swazey 1992:208), but advocates tend only to mention it in reference to the cost savings of kidney transplantation over dialysis.

18. A representative sample of the literature promoting the gift ideology is the following: Guttmann 1991; Hazony 1993; Murray 1987a, 1987b; Pellegrino 1991; Prottas 1983; Youngner et al. 1985. It should be noted that the Council of the Transplantation

Society, the National Kidney Foundation, the American Society of Transplant Surgeons, the American Society of Transplant Physicians, the International Transplantation Society, the American Medical Association, the American Hospital Association, as well as both federal and state laws, support the existing altruism-based system for organ donation. For a review of international legislation and professional guidelines prohibiting commerce in organs, see Fluss 1991.

19. Ohnuki-Tierney is especially concerned with the way the gift metaphor is used to promote transplantation in other countries, which she sees in the context of the West's cultural imperialism.

20. A representative sample would include the following: Andrews 1986; Barney and Reynolds 1989; Blair and Kaserman 1991; Blumstein 1993; Brams 1977; Butler 1985; Chapman 1983; Cohen 1989, 1991; Dukeminier and Sanders 1968; Hansmann 1989; Jaffee 1990; Matas et al. 1985; Peters 1991; Schwindt and Vining 1986.

21. There is no need to review the specific compensation forms that have been proposed. They range from direct payments on a futures market, with actuarial tables serving as the basis for predicting the likelihood of transplant useful deaths, to flat fees paid to survivors. Some of the proposals offer the kind of mathematical equations and graphs one would expect in an economic analysis of more standard markets, but here they quantify such things as "religion-based opposition to desecration of the human body" (Schwindt and Vining 1986:492).

22. Several of these authors appear to enjoy the prospect of outraging their readers, as when Cohen (1989:40) suggests that people about to commit suicide might be urged not to do so in a way that would damage transplantable organs, or when Hansmann (1989:64) recommends that insurance companies selling policies to motorcycle gangs might want to intensify their solicitation of organ contracts since cyclists have a good probability of dying the requisite death.

23. In fairness to Radin, her article, while relevant to transplantation, was not written with organ sales specifically in mind. She applied her notion of "market-inalienability" to prostitution, baby selling, and surrogate motherhood.

24. The operative cultural principal in the United States that defines which body parts may be bought and sold is not just the capacity for regeneration; bone marrow, which is governed by rules of donation, regenerates. Neither is it the notion of "surplus," since kidneys, a paired organ, may not be marketed. Rather, the boundary seems to be drawn around those bodily fluids and tissues the loss of which we experience in the normal course of our lives and/or are replaceable. This would seem to link such substances as blood, semen, hair, and ova in a category of bodily by-products that are not essential to the person.

25. There is relatively little empirical evidence on public attitudes toward compensation plans; what evidence there is suggests a high degree of opposition among all but younger adults (18–24 years old) (see Kimbrell 1993:287–288). One telephone survey (n = 800) undertaken for UNOS (Kittur et al. 1991) found substantial support (52%) for the general idea that some form of compensation, not necessarily financial, should be offered to increase donation rates. This survey did not inquire about the more extreme proposals for futures markets, but I consider it safe to predict that support would drop significantly were more commercially designed compensation plans included in the alternatives presented to respondents. In any case, a telephone survey is certainly not the best way to assess public opinion on this issue.

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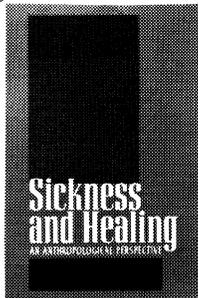
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