Special Section: Meanings and Contexts: Anthropological Perspectives in Bioethics

Denying Culture in the Transplant Arena: Technocratic Medicine's Myth of Democratization

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Introduction

In the United States, organ transfer[1] has generated a highly selective and overly specialized approach to bioethics. A dominant assumption is the myth of medical democracy: whereas professionals involved in this highly technocratic arena publicly embrace notions of medical equality, particularized practices expose another reality. The more specific ideological tenets of medical democracy read as follows: First, all potential transplant patients are equally deserving of replacement organs. Further, all citizens are entitled to equal access to these unusual commodities, which are regularly described as precious and scarce "national resources."[2] Whether the premises of medical democracy are in fact played out in daily practice, however, is another matter entirely. Organ donation is driven by a universalized sense of humanity, whereby all bodies are assumed equal beneath the surgeon's knife. Yet the social worth of individuals varies radically: children, pregnant women, the unemployed, and prisoners, for example, expose a wide spectrum of responses to certain categories of bodies. So, too, do the cultural origins of organ donors. By drawing on anthropological knowledge of sociomedical practices relevant to organ transfer, this essay explores this theme of medical democracy specifically in reference to the needs of Latinos in New York City.

Of particular interest here is the manner in which medical democratization simultaneously shields a host of participants from existing prejudices, denies economic and other forms of disparity, and mystifies the commodification of the body and its parts. Democratization can also confound ideas of difference, because its rhetoric may obstruct open discussions of race, ethnicity, and culture, categories that are far too often conflated in this particular medical realm. More specifically, democratization ironically operates as a potent form of silencing, given that it may discourage investigations of intense suffering when shaped by disparities of medical need. The ethnographic approach of anthropology can thus be especially helpful to an exploration of idealized versus actual applications of the ideology of medical democratization.

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Methodological Concerns

A fundamental methodological approach employed by anthropologists is in-depth and long-term ethnographic research. Ethnography necessitates involvement in the everyday life of a community, where the investigator is simultaneously participant and observer. Within a medical context, activities may include attending regular staff meetings and specialized events; conducting structured interviews with clinicians, patients, kin, and members of the lay community; and perusing media and archival materials. Rather than employing large-scale and anonymous telephone surveys or mailings, anthropologists more commonly rely on open-ended questioning of community members, where personal rapport with interviewees enhances the richness of qualitative data. Through such activities anthropologists strive to uncover the deeper meanings[3] embedded in human gestures, words, opinions, and beliefs. Key here is an anthropological awareness of the potential breach between idealized versus actual behaviors and attitudes: all societies have rules that govern behavior, yet the realities of life inevitably necessitate at times flexibility, at others ingenuity, at still others ignorance or even defiance.

The data reported here are drawn from nearly a decade of anthropological research based, first, in a large Midwestern city that is a major transplant center for its region and, subsequently, within Manhattan and several other East Coast cities that are home to both large transplant hospitals and procurement organizations. This research falls into three phases that focus on the lives of organ recipients and their kin (1991–1994), procurement professionals (1994–1996), and the kin of deceased organ donors (1996–present). Research activities have included active participation in two transplant patients' support groups, one procurement agency, and two donor advocacy groups; attendance at a host of related public events, including in-house hospital celebrations, donation campaigns, annual donor memorials, and two Transplant Olympics that occur biannually within the United States; as well as extensive interviewing of a host of concerned parties. Given the sensitivity of these data, I employ pseudonyms to preserve the anonymity of individuals and organizations, a standard practice guided by the discipline's professional code of ethics.[4]

In this article, I argue that the question of medical democracy within the realm of organ transfer is plagued by a host of ethical dilemmas that are readily exposed through ethnographic investigation. Among the most confounding issues involves medical versus lay understandings of race, ethnicity, and culture—factors that ultimately shape understandings of access to medical care and the disparities of organ allocation. To illustrate these themes, I begin with a case study, offered in narrative form, that focuses on the activities and concerns of a grassroots advocacy group that voices the specialized needs of Latinos in New York City.

Latinos and Liver Allocation in New York

At 9:00 A.M. on a Sunday morning in November, 1999, a breakfast caucus was held in a lavish Manhattan hotel and hosted by LLO,[5] the Latino Liver Organization, which is based in a neighboring borough. Although relatively small (its estimated membership rests in the hundreds), LLO has quickly grown within only a few years into a highly vocal grassroots organization with substantial leverage in Manhattan's political and medical arenas. A significant number of LLO's members await liver transplants, their ultimate survival compromised by Hepatitis C infection, a disease that can remain undetected for a decade or more and that has recently emerged as a serious health problem especially rampant within New York's Latino population.[6] LLO's growing prestige was immediately evident in the panel of esteemed speakers, which included influential city council members and state legislators, a highly placed member of the city's board of health, as well as several well-known transplant surgeons, all of whom had agreed to assemble at this early hour on a Sunday morning to address a select group of LLO's members.

All participants had gathered with common goals in mind—that is, to celebrate the achievements of LLO and to reaffirm the urgency of liver disease as a public health crisis within the Latino community. Nevertheless, an analysis of the more subtle aspects of the morning's presentations reveals that at important junctures lay activists and medical practitioners stood at odds with one another. More specifically, they offered competing readings (i.e., interpretations) of the local and national efforts required of Latinos in reference to a larger crisis of organ scarcity within the United States. Throughout the morning, LLO activists clamored for more financial and structural support from state, insurance, and medical institutions that would enable terminally ill Latinos to receive liver transplants. Clinicians, on the other hand, while acknowledging the seriousness of Hepatitis C infection, nevertheless consistently expressed the need for all citizens—including Latinos—to consent more often to organ donation. It mattered little that this gathering was peopled primarily by individuals who could not be organ donors and who instead were in dire need of transplants to save their lives. Both parties offered their statements with full knowledge that Latinos define an important category of organ donors, their numbers significant enough to account for a recent upsurge in donation rates both within New York and nationally. UNOS (United Network for Organ Sharing), the federally funded organization that oversees the distribution of organs across the nation, had recently announced in its 1998 annual report that "the number of . . . Hispanic [cadaveric] donors increased substantially," up 7.8% from the previous year, compared to an overall national increase of 5.6%.[7] Against such statistics, the Sunday LLO breakfast meeting offers a glimpse of much larger ethical conflicts shaped by disparate readings of ethnicity. To decipher these readings we must turn to more general understandings of disparity within the medical arena of organ transfer.

Ethnicity and Its Ethical Concerns

Specialized forms of medical anxiety over organ scarcity frame discussions of organ transfer, because this realm is consistently described as being limited or even undermined by a chronic shortage of human organs. Such anxiety defines a major impetus behind donation campaigns; further, it fuels the devotion that drives the difficult work of procurement staff throughout this country. All involved parties—be they transplant surgeons, recipients, procurement specialists, or donor kin—are united in their fervor to increase donor awareness and, thus, the nation's supply of body parts. Further, all parties embrace values central to the theme of medical democracy. In other words, all patients in need are equally deserving of expert medical care that will ultimately deliver to them organs of the highest quality.

Ethical problems associated with cultural pluralism nevertheless have long plagued technocratic medicine.[8] Specifically in reference to transplantation, obscured references to social class, ethnicity, and race define significant rallying points for this theme of democratization. Interestingly, however, any direct mention of unequal access commonly generates responses of anger from any of these parties, all of whom assert their devotion to a medicalized understanding of equal opportunity. As a result, when among their peers, professionals especially are frequently discouraged from discussing medical inequality resulting, in the end, in a potent form of silencing.

Unfortunately, such silencing serves to deny, rather than problematize (that is, expose and then resolve), the often glaring disparities experienced by people of color in need of transplants. For example, New York City's clinicians frequently and adamantly insist that they erect no barriers that would exclude particular groups from quality care in this highly technocratic realm of biomedicine. The liver wards of the city's hospitals offer testament to this, given that a substantial number of those receiving medical care are, in fact, Latinos suffering from the devastating effects of end-stage Hepatitis C infection. Experiences in other arenas, however, reveal competing narratives. Membership in the city's largest support group for liver transplant recipients consists almost exclusively of non-Spanish-speaking Whites of middle-class origins; in contrast, the annual donor memorial hosted by this same group is attended overwhelmingly by Latino donor families, and so, partially in response to this disparity, LLO was formed. As the case example above illustrates, discussions of potential disparity across color and class lines are consistently silenced by the force of medical authority even when evidence in other spheres may prove contradictory. Race and class are explosive topics considered by professionals too dangerous for open public debate, given that any exposure of disparity may undermine the efforts of an already fragile realm of medical supply and demand.

This denial of disparity offers evidence of larger ideological constraints inherent to the transplant industry. Interestingly, discussions so characteristic of professional transplant forums inevitably focus on the current scarcity of organs, yet they rarely place blame squarely on the transplant industry itself. There is little mention of transplant surgery as a popular and lucrative form of medical specialization; the increased tendency to accept only patients who can pay up front for their surgeries; or retransplantation for former recipients as yet another source of organ demand. Rather, the lay public remains culpable: this is nation of selfish individuals who withhold and thus waste these precious national resources. Thus, transplant surgeons responded in typical form at the Sunday LLO gathering in New York: the primary concern should be to alleviate the organ shortage by encouraging all members of this nation, regardless of their backgrounds, to give of themselves for society as a whole. Such statements are driven by civil constructions of the common good, where the actions of transplant professionals should not be influenced by patients' social backgrounds. Regardless of our class, culture, gender, and, most recently, age,[9] we are all equal, and together we must share the responsibilities of donation. The credibility of medical democratization hinges on an analysis of competing understandings of, first, who, in fact, gives up their organs; second, how such "gifts of life" are offered and under what circumstances; and, third, who ultimately holds rights to the organs taken from donors' bodies.

The Obscured Origins of the Gifts of Life

Competing (mis)readings of sociocultural difference undermine the potential for integrating professional versus lay understandings of the origins of transplantable organs. One of the more troubled issues involves the obscuring of the identities of organ donors: that is, from whom, or what social categories of patients, are organs taken? This is an issue that matters deeply to the surviving kin of organ donors who nevertheless remain anonymous within the realm of organ transfer. Social categories are nevertheless of statistical importance to professionals. For example, each time a potential donor is identified in a hospital bed, procurement professionals are required to reduce donors' identities to particular categories recognized by UNOS. These include "Caucasian," "Hispanic," "African-American," and "Asian." Such seemingly discrete categories in fact frequently confound these professionals. On the one hand, donor labeling is a crucial step required for tissue and thus genetic typing; yet professionals frequently conflate race with ethnicity and, thus, culture. "Hispanic" emerges as a particularly problematic category. In New York City, Latino or Hispanic donors are often recategorized as either "Caucasian" or "African-American," as procurement professionals rely on visual readings of donors' physical characteristics that then obscure their social identities. In New York, for example, a fair-skinned Mexican or Puerto Rican is typically categorized as "Caucasian," whereas Dominicans (like Haitians), if fairly dark skinned, are generally labeled as "African-American."[10] Latino donor kin, grassroots medical educators, and activists, however, regard such actions as unjust forms of medical relabeling that immediately and irreversibly obliterate the origins of donated organs. Thus, although Hispanics are hailed by UNOS as a growing category of donors nationwide, many donors remain invisible within or lost to the bureaucratic demands of technocratic medicine, transformed into other ethnic categories that deny the relevance of culture. Against this background emerges the seeming insensitivity of surgeons' statements at the LLO Sunday gathering described earlier, because they may remain unaware of the fact that many of the organs they receive are drawn from Latino bodies.

The Politics of Giving

One might ask why, ultimately, the ethnic identities of organ donors should matter at all. If we turn to the act of donation itself, however, it becomes clear that donor origins are of intense interest to both lay kin and professionals in the realm of organ transfer. A national myth of sorts is that organ donors are typically White, middle-class youth who suffer irreparable brain damage from highway accidents. This is only part of the story, however: as reported at a procurement conference a few years ago, 20% of all donors within the United States are in fact victims of gunshot wounds.[11] Careful police surveillance of seatbelt use and drunken driving has decreased highway fatalities and, thus, some procurement organizations may rely heavily on forms of urban violence as sources for potential donors. In Manhattan, such factors are key, given that many residents do not drive; further, road fatalities are at an all time low, the city being heralded recently as among the safest places within the nation to be a pedestrian.[12] My own research with donor kin reveals that many organ donors were in fact victims of homicides and suicides, most often involving handguns. Young men of color drawn from the nation's marginalized urban zones are now regarded by procurement staff as valued donors who may redeem their social worth by giving their body parts to others who lie at the brink of death. A host of troubling strategies may be employed to convince surviving kin to grant consent to donation. Among these is the veiled threat of criminal investigation.

The words of one interviewee illustrate the power of such a strategy. As Manny, a Latino procurement specialist explained,

> . . . I have to tell you something . . . especially when you're dealing with minorities. . . . See, there's also the medical examiner [M.E.]. When I think of minorities, I think, thank God for the medical examiner. You just bring it up and they [the surviving kin] lose control. They know about what it means, they've heard about the M.E.—that the body is going to be taken over. . . . They'll lose control over what happens to the body, and they know someone is going to be found guilty of what happens. They can no longer protect that person. So they reconsider [donation]. But . . . I want you to understand that I only use [this tactic] . . . as a last resort. Of course, the M.E.[s] really can step in and stop a donation—because they are afraid that if you open the body and remove the organs you may destroy some evidence.

The role of the medical examiner in shaping the outcome of organ procurement is underscored as well by J. L. Burton, chief medical examiner for Atlanta. As he explained in a report prepared by the National Kidney Foundation,

> when the medical examiner releases a cadaveric organ or tissue to an agency, he must be sure that he is not jeopardizing some part of a criminal investigation, which is not unusual because the most suitable donors tend to die of trauma.[13]

Manny feels his actions are justified because they enable him to rescue an otherwise unproductive person for the common good. This ideal of social transformation is frequently voiced by other procurement professionals. It is also embraced by donor kin as a legitimate reason to grant consent, especially when they perceive a donor's life as unproductive or destructive, or when a life ended in violence. Interestingly, though, such stories are excluded from publicized reports of organ transfer because they involve deeply troubling events too closely linked to the larger realm of urban violence within this country.

Thus, although organs are taken from murdered young men of color to save the lives of other anonymous strangers, the origins of their organs are regularly obscured. Organ recipients always receive highly abbreviated biographies of their donors: typically they are only told the donor's age and gender and, usually, within which states or regions of the country they resided. Rarely, however, are recipients told of the circumstances surrounding donors' deaths. Further, ethnicity and social class are not reported. The only exceptions I have encountered to date involve African-American recipients, who may know that their donors were Black. Further, unlike the majority of White middle-class recipients, they might not be shielded from tales of violence, but, rather, they alone are told that their donors died from gunshot wounds to the head. As one female recipient explained, this happens because "they [that is, transplant professionals] just assume that violence is a way of life for us."

Who Holds Rights to the Dead?

Amidst chronic concerns over organ shortage, a question that plagues organ transfer is who, ultimately, holds rights to donors' bodies?[14] Or phrased in another way, which recipients should receive these scarce body parts? In response, an unusual form of national fragmentation has emerged as a dominant and highly politicized theme, where states' rights[15] are asserted with increasing regularity. In November, 1999, Donna Shalala, U.S. Secretary of Health and Human Services, proclaimed at a news conference in Milwaukee that "'The hoarding of organs' for transplants by a state or a region 'is both immoral and unethical'."[16] In short, of concern here is whether organs are scarce *local* or *national resources*. This concern shapes a large-scale and heated debate over new federal guidelines set for liver allocation: briefly, Shalala's reforms privilege those at the brink of death listed on a national registry over a local state's inhabitants whose respective health statuses bear better chances of surviving surgery.[17] Livers have defined a special focus in this heated debate because total liver failure ensures immediate death, given that no artificial technologies exist that can sustain a patient's life, as is the case for other major organs. A common concern voiced within the transplant community is that smaller hospital centers will suffer from such reforms, because they generally lack the technology and services needed to sustain high-risk patients. Another related battle focuses on regional rights to donors' bodies, where Wisconsinites, for example, now assert first rights to the body parts of local citizenry. This theme of states' rights to the dead is now being defended vigorously, openly, and heatedly in public gatherings that involve transplant and procurement professionals, recipients, and surviving donor kin, who collectively assert that their dead should remain on local soil.[18]

Interestingly, current arguments that advocate decentralization actually reflect older, silenced ones about ethnicity and race. Transplant professionals often resist placing patients on recipient waiting lists if they detect racist sentiments; in one hospital where I have conducted research, staff disqualified two middle-aged White men whose racist remarks made it clear they would only accept organs from White donors. Although not publicized, donor guidelines do, nevertheless, permit next-of-kin to specify that donor organs be placed only within the bodies of certain categories of people. For example, decisions to place organs with members drawn from vulnerable populations—such as young children or people of color—are openly applauded within the transplant arena by both professionals and lay participants. One recent and highly celebrated example involved a well-known Latino church leader based in Washington, D.C., who received the heart of one of his Latina parishioners in honor of a request voiced by the donor herself before she died. Cases such as this are celebrated in large part because they assert the importance of undervalued cultures and communities. They also circumvent the oppressive social forces associated with the bureaucratic hegemony of the nation's medical technocracy that regularly determine who in fact can receive a donor's organs.

Conclusion

In conclusion, organ transfer clearly defines a murky ethical realm. Organ donation campaigns are driven by a universalized sense of humanity, where *all* bodies are equal. In reality, however, the medicalized social worth assigned both to organ donors and living recipients is far from uniform, where the myth of medical democratization squelches debates about medical justice. Although the language of equal opportunity is pervasive, the ideals of democratization may nevertheless operate as a potent form of silencing with variable results. Whereas such rhetoric is designed to combat racist sentiments, ironically it also obstructs open discussions of race and culture—categories that far too often are conflated in this particular medical realm. In still other contexts, identity is forcefully asserted. Nowhere is this more evident than in the example of national fragmentation, as states claim rights to local citizens' body parts. As such, current trends in organ procurement obliterate some identities while asserting the importance of others. Thus, if we are to address these problems openly and honestly, we must acknowledge that currently medical democratization is, sadly, often reduced to a form of technocratic rhetoric that in fact obscures or denies serious disparities. Where the control of such precious commodities is at stake, localized states' identities are asserted; but where the cultural origins of donor organs might matter, the rhetoric of medical ethics ultimately dehumanizes the nation's dead. Clearly, the theme of medical democratization requires careful and critical scrutiny, as well as open, candid discussion involving the equal participation of professionals, donor kin, recipients, and activists. Such an approach is essential if we are to understand the ethical dimensions of difference, especially in reference to medicalized constructions of ethnicity, race, and, most importantly, disparity in the realm of organ transfer.

Notes

1. To underscore their dependency on one another, throughout this article the expression *organ transfer* encompasses the inseparable realms of organ donation, procurement, and transplantation.
2. McChesney LP, Braithwaite SS. Expectations and outcomes in organ transplantation. *Cambridge Quarterly of Healthcare Ethics* 1999;8:300; for an example from Canada, see: Yoshida EM. Selecting candidates for liver transplantation: a medical ethics perspective on the allocation of a scarce and rationed resource. *Canadian Journal of Gastroenterology* 1998;12:209–15.
3. Geertz C. *The Interpretation of Cultures*. New York: Basic Books, 1973.
4. American Anthropological Association. Code of Ethics, June, 1998. *Anthropology Newsletter* 1998:19–20.
5. Pronounced "yo" (reminiscent of the first-person singular pronoun in Spanish).
6. In 1998 Mayor Giuliani of New York City declared April as Hepatitis C Awareness Month. He stressed, "It is estimated that 4.8 million Americans are infected with Hepatitis C, and that as many as 12,000 die from the condition every year." In this same context, health activist Debbie Delgado Vega further underscored that "Education can help eliminate this deadly virus and the need for liver transplants among all New Yorkers with Hepatitis C, especially within the Latino community" (Press release, 17 Mar 1998, Office of the Mayor of the City of New York).
7. United Network for Organ Sharing (UNOS). Cadaveric organ donation increases 5.6 percent in 1998. *Update* 1998;Jun:3.
8. Caws P. On the teaching of ethics in a pluralistic society. *Hastings Center Report* 1978;8:32–9; and Davis-Floyd R, St. John G. *From Doctor to Healer: The Transformative Journey*. New Brunswick, N.J.: Rutgers University Press, 1998.
9. See note 7, UNOS 1998, p. 1.

10. I wish to thank physical anthropologist F. Jackson for her provocative insights on the conflation of ethnicity and race in the medical literature; for comparative comments concerning "Asian American" as a racial category, see: Ikemoto LC. The fuzzy logic of race and gender in the mismeasure of Asian American women's health needs. *University of Cincinnati Law Review* 1997;65(3):799–864.
11. Roels L, ETCO President. Address delivered at the annual meeting of the North American Transplant Coordinators Organization (NATCO), Boston, 31 Jul 1995.
12. Lueck TJ. New York City wins an award for WHAT? Ties with far town in traffic safety as Auto Club cites a drop in deaths. *New York Times* 23 Sep 1999:B1, B6.
13. Bowden AB, Hull AR. *Controversies in Organ Donation: A Summary Report*. New York: The National Kidney Foundation, 1993:14; see also Timmermans S. Five vultures and one dead body: claiming jurisdiction and maintaining expertise in death investigation. Paper delivered on the panel "Jurisdictions of Authority and Expertise in Science and Medicine," Annual Meeting of the American Anthropological Association, November, 2000.
14. For discussions of body ownership and commodification see: Andrews LB. My body, my property. *Hastings Center Report* 1986;16(5):28–38; Annas GJ. Whose waste is it anyway? the case of John Moore. *Hastings Center Report* 1988;18(5):37–9; Belk RW. Me and thee versus mine and thine: how perceptions of the body influence organ donation and transplantation. In: Shanteau J, Harris R, eds. *Organ Donation and Transplantation: Psychological and Behavior Factors*. Washington, D.C.: American Psychological Association, 1990:139–49; and Sharp LA. Commodified kin: death, mourning, and competing claims on the bodies of organ donors in the United States. *American Anthropologist* 2001;103(1):112–133.
15. My use of the expression "states' rights" is not meant to imply a particular political orientation, even though it is generally associated with conservative responses to federal civil rights actions decades ago. I seek instead to underscore the theme of national fragmentation.
16. Marchione M. Shalala slams 'hoarding of organs,' demands fairer system: she also proposes a 10-point plan to improve children's health. *Milwaukee Journal Sentinel* 8 Nov 1999.
17. For overviews of the new guidelines, including a discussion of local versus national rights to donated organs, see: Thomasma DC, Micetich KC, Brems J, VanThiel D. The ethics of competition in liver transplantation. *Cambridge Quarterly of Healthcare Ethics* 1999;8:321–9; and Stolberg SG. U.S. urges new rule on sharing donated organs. *New York Times* 3 Jun 1998:A14.
18. For interesting comparative data on Europe see: Hogle LF. *Recovering the Nation's Body: Cultural Memory, Medicine, and the Politics of Redemption*. New Brunswick, N.J.: Rutgers University Press, 1999.