

The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants

N. Scheper-Hughes*

Organs Watch 232 Kroeber Hall, University of California, Berkeley, CA, USA

*Corresponding author: Nancy Scheper-Hughes, nsh@berkeley.edu

Medical anthropology can bring to living donor transplant useful insights on the nature of gifting, family obligations, reciprocity and invisible sacrifice. Whereas, ethical reflections and debates on the marketing of tissues and organs, especially sales by living strangers, have proliferated to the point of saturation, the larger issue of the ethics of 'altruistic' donation by and among family members is more rarely the focus of bio-ethical scrutiny and discussion today, though of course it was much debated in the early decades of kidney transplant. As the proportion of living over deceased donors (especially of kidneys) has increased markedly in the past decade, the time is ripe to revisit the topic, which I shall do via three vignettes, all of them informed by my 10 years as founding Director of Organs Watch, an independent, university-based, anthropological and ethnographic field-research and medical human rights project.

Whereas living-related (altruistic) and living-unrelated (commercial) donation are often treated as very different phenomena, I will illustrate what social elements are shared.

In both instances, paid kidney sellers and related donors, are often responding to family pressures and to a call to 'sacrifice'.

Key words: Age, family sacrifice, gender, living donors

Received 19 September 2006, revised 9 November 2006 and accepted for publication 14 November 2006

'There is nothing like a crisis to galvanize a family, to set its silent wheels in motion.'

David Biro, 'Silent Bonds', 1998

As the proportion of living over deceased donors (especially of kidneys) has increased markedly in the past decade, the time is ripe to revisit the topic, which I shall do via a critical medical anthropological reflection

informed by my 10 years as founding director of Organs Watch, an independent, university-based, anthropological field-research-based, medical human rights project (1,2) (<http://sunsite.berkeley.edu/biotech/organswatch/>). Whereas living-related (altruistic) and living-unrelated (commercial) donation are often treated as very different, even contradictory, phenomena, I will show what social elements are shared, in particular, the role of family pressures and to a call to 'self-sacrifice'.

Family Bonds or Family Bondage?

In a chilling essay (3) followed by a book length memoir (4) of his encounter with Paroxysmal Nocturnal Hemoglobinuria (PNH), a rare blood disease destroying his blood cells, David Biro explained why he felt that any one of his sisters should unhesitatingly offer themselves as blood marrow donors. 'That is what families *are supposed to do*', the young doctor stated, even mildly dysfunctional families like his in which the older brother and his baby sister were, before and after the donor transfer, virtual strangers to each other. Biro describes his younger sister, his future donor: 'My day to day knowledge of Michele was curiously incomplete. . . We rarely talk about anything deeper than a movie or a meal. . . I loved her in the distracted way you love a person whose external data are familiar but whose internal workings are a pleasant mystery. . . [but] now I needed her.' (All quotes are from 'Silent Bond', 1998:94.)

Biro felt justified in putting his younger sister's life—the one whose near perfect genetic match turned out to be David's 'jackpot' number—and her mobility on hold indefinitely. A free spirit who had trekked across the Yukon and worked with disabled children in rural Guatemala, Michelle interrupted her life and her travels to serve her brother's medical needs. Although a vegetarian, she agreed to eat plenty of red meat and sing the praises of a slab of Canadian bacon. The possible risks to the donor (5)—excessive pain, delayed or prolonged recovery, anesthesia reactions, injury to tissue, bone or nerves were never mentioned.

This scenario fits the normative transplant discourse in which gifting and altruism are assumed among close friends and kin. It is what any one of us would hope for ourselves were we in the same predicament, either as donor or recipient. But Michelle's donor role was not over after the transplant. Now that 'she had literally become a part of me', Biro wrote that he wanted to keep her close by him

in the event he might suffer a relapse that would require more of her marrow. He admitted to feeling resentment whenever his sister spoke of plans for far-flung journeys and he demanded that she cancel a trip to Alaska. Michelle, the silent and invisible object lesson in this medical parable, quietly acquiesced, or so we assume. Biro saw his medical needs as an automatic future claim over his sister's body, which sustained him physically and psychologically. Hegel might have referred to this arrangement as a master–slave dialectic, marked by mutual dependencies and invisible violence and sacrifice.

At the close of his essay Biro boasts that he never thanked his sister because 'to do so would have violated the pact of silence that brothers and sisters feel compelled to uphold'. This 'pact of silence' is what anthropologists call a 'public secret', something known by all but unstated because of the extreme fragility of the social situation. Here the 'secret' concerns fairly primitive blood claim by one sibling on the other. A living donor in Brazil said that her surgeon had extracted a similar promise that she never speak of her gift within the family as it would be unfair to the recipient. The gift must be invisible, thus maintaining a 'family myth' capable of erupting later on.

Biro's memoir was highly praised as 'the work of a doctor who has the soul of a "poet"'. There is no mention in the reviews of David's donor, illustrating my point that living donors are almost as invisible as deceased ones. Both are faceless 'suppliers' of a scarce commodity. Over time the transplant experience was reduced 'to a wisp of memory' as each moved on in their lives. Biro went back to 'not knowing Michelle and she to not knowing me'. This narrative speaks less to family bonds than to family bondage, less to gifting than to poaching.

The Gender of the Gift

If Biro's sister had been the patient, would David have interrupted his active life and put his body on the line to serve her needs? International data indicate a gender bias in living donation, with females the more likely donors (6–10). The Organs Procurement and Transplantation Network (OPTN) lists 2299 (living) females and 1637 males who have donated organs in 2006; the gender gap is greater for other years. Wives are far more likely than husbands (36–6.5% in one survey) to donate a kidney to a spouse (8, 10). In Iran under a government regulated system of paid donation, women are the primary paid donors and men the primary receivers of those purchased organs (7).

Rather than celebrate the 'altruism' of women worldwide, we ought to be paying attention to the social pressures exerted on them to be living donors. A pediatric transplant surgeon in Brazil explained the excess of female donors in his clinic: 'It is only natural that mothers are the donors within families. I tell [fathers] that the mother has already

given life to the child, and now it is his turn. But most men feel that organ donation is a *womanly* thing to do'.¹ A transplant surgeon in Recife, Brazil, stated that mothers were the preferred family kidney donors on the grounds of tissue compatibility. You always knew who the biological mother was, while biological fathers were uncertain.

Anthropologists entertain different assumptions than physicians about the nature of families, altruism, gifting, and human sacrifice. Families are often violent and predatory, as inclined to abuse and exploit as to protect and nurture their members. Gifts are never 'free'; they inevitably come with strings, making the recipient beholden in crucial ways (11). Every gift is both altruistic and indebted, spontaneous and calculated. Gifts demand counter-gifts, even though time may elapse and the return gift may or may not be in kind. Pure altruism does not exist, except perhaps toward one's children, and bio-evolutionists would point out that parental sacrifice hides another sort of (genetic) self-interest.

Organ capture within families involves an intensely private dynamic that often escapes the most careful medical professionals. In societies characterized by a high degree of male dominance pressure is frequently exerted on lower status, poorer, female relatives to 'volunteer' as donors. The tendency is to choose the least valuable, least productive family member, the unemployed single maiden aunt, for example. A spinster teacher from a small town in Brazil was 'nominated' by her siblings to be a kidney donor to her younger brother. 'Zulaide' agreed but she resented the imposition. To make matters worse the transplant failed; her kidney was rejected and her brother died. When Zulaide suffered from vague symptoms attributed to her nephrectomy, her complaints were dismissed by the transplant surgeon as 'neurotic', as 'donor regret', as a kind of 'compensatory neurosis suffered by a childless woman who never succeeded in anything in life, not even in being a donor'. The remark revealed the physician's barely concealed contempt for this low status female. During a meeting of the Bellagio Task Force on organs trafficking (12) Abdullah Daar argued that kidney selling would actually protect low status women in the Middle East from being coerced to serve as altruistic family donors.

In the early decades of transplant physicians were cautious about living donors, realizing that relatives of the sick were often under pressure to donate. Thus, they went out of their way to protect designated donors from having to do so, often providing them with a medical alibi even though this went against their own desires to see their patient transplanted. One surgeon, cited by Fox and Swazey (1978: 386) believed that living donation involved such a degree

¹Anthropologists are honor bound by our professional ethics to conceal the names of our research informants if they request to remain anonymous, as in this case.

of interdependence and over-identification between donor and recipient that it ought to be a taboo, similar to the incest taboo. That caution has evaporated as living donor transplant became routine.

The Tyranny of the Gift

In some societies, like Japan, where the demands of gift giving are very elaborate, individuals fear being the recipient of a large and impressive gift that can humiliate the receiver who has no possibility of repaying it (13). Fox and Swazey (14) first referred to the 'tyranny of the gift' to describe the onus of organs gifting:

'The gift the recipient has received from the donor is so extraordinary that it is inherently unreciprocal. It has no physical or symbolic equivalent. As a consequence, the giver, the receiver, and their families may find themselves locked in a creditor-debtor-vice that binds them to each other in a mutually fettering way.'

The gift-giver may lord it over the recipient and may feel proprietary toward the recipient of their largesse. In my Organs Watch files are examples of the following: a father who gave his 16-year-old son a kidney continues to control his movements well into adulthood, even reading and censoring his love letters; a sister-donor refuses to allow her younger brother to ride his motorcycle or go out to parties where alcohol was served because it might damage 'her' kidney; a donor aunt who rejects the engagement of her niece to a man the aunt deems unworthy of the person *whose life she had saved*. In each case the donor did not give but 'lent' a kidney to the patient.

Thus paying a stranger for a kidney can seem liberating to the buyer. A young Israeli woman who traveled to Durban, South Africa, in 2003 where she was transplanted with a kidney purchased from a poor Brazilian said she had done so to avoid asking a relative to serve as her donor:

'To ask someone from inside your own family, it's too difficult. It's like you owe him your life, so it's always a big problem, always hanging like a weight on you. If I would have to see my donor everyday, I would have to be thanking him all the time and that would be awful. I didn't want to see the face of the kidney seller, so that I would never have to think about him again. I paid for it. He accepted it. It's done, over. His kidney inside me belongs to me now, the same as if it were a cadaver kidney.'

By transforming the 'gift' of an organ into a 'commodity,' the burden of debt to the giver is expunged. But as I describe next, family pressures and sacrifice are present

even in the context of kidney buying and selling. In both instances—living-related and paid donation—weaker family members are recruited to sacrifice themselves in the interests of the family good.

Sacrificial Violence in Living Paid Donation

In the watery slum of Banong Lupa, Manila, a site of active kidney selling, I stumbled on a troubling phenomenon. The obligation to sell a kidney to provide basic necessities for one's family initially fell on mature male heads of households. Over time, kidney selling became routine and perceived as a meritorious act of self-sacrifice, demonstrating the lengths to which a good husband and father would go to protect his family. On a return to Manila in 2003 (15) as part of a documentary film team, I observed many more scarred bodies among young men and boys, even teenagers, who had lied about their age to be accepted as paid donors in public and private hospitals there. Sixteen-year-old Faustino was recruited by his maternal uncle, Ray Arcela, a former kidney seller. 'It's *your turn*', Uncle Ray told the boy reminding him that Faustino's father and his two older brothers had already sold a kidney. The \$2000 earned per kidney never got these large families out of trouble. Similarly, Andreas was 17 when his mother begged him to sell a kidney so she could purchase the cases of beer, cokes and hard liquor she sold out of her shack. A good son, Andreas could not refuse his mother's request. Kidney selling had become a rite of passage among adolescents, and a kidney scar across the torso of a teenager was as common as a large tattoo. Just as tattoos signified membership in a youth subculture, the long scar across the torso symbolized *machismo*, courage and family loyalty, indicating the boy's attempt to support his parents.

While the social pathologies involved in kidney selling may seem distant from normative practices of altruistic kidney donation, I am suggesting that there are dimensions of family sacrifice, betrayal and coercion hidden within both forms of living donation, related and commercialized.

My final scenario is, perhaps, the most controversial.

Old Bodies, Young Donors

The number of kidneys transplanted in patients over 70 years has increased markedly over the past decade. As the US population ages, and as transplant has become routine, older patients are demanding the better quality of life that a transplant can bring. In the United States, with its highly *individualistic* notion of equality, there is a strong reluctance to disqualify the old from the benefits of transplant, and their physicians are reluctant to discourage them. Consequently, elderly patients are the fastest growing group requiring renal transplant (16). As of 1 November 2006,

10 628 patients over 65 are wait listed for an organ. A hospital in Pennsylvania recently transplanted a kidney from a deceased donor into a 90-year-old patient. In some parts of Europe and the United States the demand has been partially offset by offering elderly patients older, sicker organs, euphemistically referred to as 'extended criteria' organs (17). While there are ethical quandaries in so doing, old-to-old organ transplants, expresses a kind of social justice and equity. From a purely social utilitarian perspective the practice enhances the longevity of younger organs reserved for 'younger' recipients.

Another solution is more troubling, an increase in living donation by adult children and grandchildren for their parents and grandparents. Of the 1684 kidneys transplanted to patients over 65 in 2003, 513 were from living donors and 295 from adult children of the recipients. Children in their 30s, 40s and 50s gave kidneys to parents in their 60s and 70s. An ethnographic study by Sharon Kaufman at the UC San Francisco (18) identified a subtle practice through which children were recruited by transplant professionals to donate to their elders. This practice violates a cultural norm in American society where it is not generally expected that children be unstintingly devoted to their parents, something that generations of immigrants from Europe were happy to leave behind. Rather, American parents are expected to give unstintingly to their children (19). Thus, statistics compiled by the kidney transplant registry in the 1970s show that within families mothers were the primary living-related organ donors, followed by fathers and siblings. Less than 1% of living donation was of children to their parents (20).

What has happened since that period? The current situation reflects the impact of the availability of extreme life-saving measures on family dynamics. As aging and death are increasingly viewed as the result of 'technological failures' rather than as human inevitability, older patients grasp for technological straws, and their physicians collude with them. Kaufman captures the moment in the following example. *Physician to a 71-year-old woman*: 'Getting you a live donor kidney would be a great thing. And the sooner the better. It could be five or six years if you wait for a cadaver donor' (2006: 85). Today, kidney patients are aware of the added value of a live over a dead donor. In some circles of patient activism, the preference for a 'fresh' kidney from a living donor is so strong that deceased donors are now viewed with distaste. 'A fresh live organ is the most *natural*, the best choice', a transplant recipient in New York City told me. A dapper gent in his 80s explained why he had chosen to travel for an illegal transplant with a (paid) young living donor from Romania:

'Why should I have to wait for a kidney from an accident, a kidney that was pinned under a car for many hours, then kept on ice for several hours. ... That kid-

ney is not going to be any good! Even worse, I could get the organ of an elderly person, or an alcoholic, or a person who died of a stroke. That kidney is all used up! It's much better to get a kidney from a healthy person.' (21)

While it is easy to distance oneself from the experience of transplant tourists who are willing to break the law to get what they want, the logic employed by some doctors and their elderly recipients is not dissimilar. Kaufman recorded the words of a physician to a 77-year-old man in California with heart disease: 'Realistically, *you will have to have someone donate you a kidney* if you ever want to get one'.

This 'quiet revolution' in kidney transplant raises many issues and is purchased at a great social cost, in the obligations felt by children to forfeit a 'spare' kidney for the elderly parents. Lungs and half livers are the next goalpost in sight.

Restoring a Social Ethic to Transplant

In the early days of transplant living donation was the exception to a 'preferential option' for the brain dead donor. That initial ethical shudder, that hesitancy to take from the young and the healthy to rescue the old and the mortally ill is no longer an obstacle. While the medical benefits of living donation for the recipient and the psychological and spiritual benefits for the donors have been discussed (22) I want to recover the discomfort in dipping too readily into the bodies of living donors. I am suggesting, if not a moratorium, a *slowing down* of the use of living donors, especially young ones. My concerns are not with the medical risks of living donation but with the less visible social and familial conundrums it provokes. These fall outside the view of transplant professionals and require the skills of the medical anthropologist and sociologist, who even more than bio-ethicists, are the real 'strangers at the bedside' of transplant patients.²

Many specialists in the field would reply that deceased donors can never provide sufficient organs. They are unwilling, however, to examine the waiting list to see if futile cases cannot, in good faith, be removed and to establish age limits that would decrease the list by several thousand. Doing so, however, would put more pressure on living donors to rescue disqualified loved ones, and on very sick or very old patients to search for illegal transplants abroad, or to list patients online (<http://www.matchingdonors.com>) in a search unaccompanied by medical regulation or surveillance. Obviously, living and deceased donation impact each

²This is a reference to David Rothman's classic work, *Strangers at the Bedside: A History of how Law and Bioethics Transformed Medical Decision Making* (1991). New York: Basic Books.

other and these two systems of procurement have to be considered conjointly.

Ethical solutions are not always palatable. Rather than find new ways to compensate or honor living donors we need to continue the struggle to increase deceased donation. While awaiting the results of stem cell engineering, the development of advanced mechanical kidneys and xeno-transplant, we ought to consider options that have worked elsewhere. Presumed consent, widespread in central Europe, preserves the value of organ transplant as a common social good in which no one is included or excluded on the basis of their ability to pay. Living donation, however, should be consigned to a back seat as an exceptional back-up to deceased donation.

Acknowledgments

Research and travel support for this project was provided through grants from the Open Society Institute, New York City, and the University of California, Berkeley. This essay was written while the author was a fellow at the Radcliffe Institute for Advanced Study, Harvard University, Cambridge, MA, USA.

References

1. Scheper-Hughes N. The global traffic in organs. *Curr Anthropol* 2000; 41: 191–224.
2. Scheper-Hughes N. Rotten trade: Millennial capitalism, human values, and global justice in organs trafficking. *J Hum Rights* 2003; 2: 197–226.
3. Biro D. "Silent bond", *New York Times Sunday Magazine*, October 11, 1998: 94. All quotes cited are from this opinion piece.
4. Biro D. *One hundred days: My unexpected journey from doctor to patient*. New York: Vintage, 2001.
5. Confer DL, Leitman SF, Papadopoulos EB et al. Serious complications following unrelated donor marrow collection: Experiences of the national marrow donor program. *Blood*. 2003; 102: 490.
6. Biller-Andorno N. Gender imbalance in living organ donation. *Med Health Care Philos* 2002; 5: 199–204.
7. Khajehdehi P. Living non-related versus related renal transplantation—its relationship to the social status, age and gender of recipients and donors. *Nephrol Dial Transpl* 1999; 14: 2621–2624.
8. Kayler LK, Rasmussen CS Dykstra DM et al. Gender imbalance and outcomes in living donor renal transplantation in the United States. *Am J Transpl* 2003; 3: 452.
9. Ojo A, Port FK. Influence of race and gender on related donor renal transplantation rates. *Am J Kidney Dis* 1993; 2: 835–841.
10. Zimmerman D, Donnelly S, Miller J, Stewart D, Albert SE. Gender disparity in living renal transplant donation. *Am J of Kidney Dis* 2000; 36: 534–540.
11. Mauss M. *The gift*. New York: W.W. Norton, 1967.
12. David R, Rothman DJ, Rose E, Awaya T. The Bellagio Task Force report on transplantation, bodily integrity, and the international traffic in organs. *Transpl Proc* 1997; 29: 2739–2745.
13. Margaret L. *Twice dead: Organ transplant and the reinvention of death*. Berkeley: University of California Press, 2002.
14. Fox R, Judith S. *Spare parts* New York: Oxford University Press, 2002: 40.
15. *Transplant Tourism* (2003) was produced and directed by Vancouver-based filmmaker David Paperny for Paperny Films in association with CBC Newsworld.
16. Oniscu G, Brown H, Forsythe J. How old is old for transplantation? *Am J Transpl* 2004; 4: 2067–2074.
17. López-Navidad A, Caballero F. Extended criteria for organ acceptance. Strategies for achieving organ safety and for increasing organ pool. *Clin Transpl* 2003; 17: 308–324.
18. Kaufman S, Russ A, Shim J. Aged bodies and kinship matters. *Am Ethnologist* 2006; 33: 81–99 (quotes are from page 82).
19. Schneider D. *American kinship: A cultural account*. Chicago: University of Chicago Press, 1968.
20. Fox R, Swazery JP. *The courage to fail: Social view of organ transplants and dialysis*. Chicago: University of Chicago Press, 1978: 386 (footnote 6).
21. Scheper-Hughes N. Commodity fetishism in organs trafficking. In: Scheper-Hughes N, Wacquant L, eds. *Commodifying bodies*. London: Sage, 2002.
22. Inglefinger JR. Risks and benefits to the living donor. *New Engl J Med* 2005; 353: 447–449.