



Bodies of Apartheid:

the Ethics and Economics of Organ Transplantation in South Africa

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This is work in progress, and as I always like to warn it is a thinking aloud in public. The research in which I am engaged is preliminary, ethnographic, descriptive, anecdotal if you will, and peripatetic -- or multi-sited. Today I will concentrate on one major site in which I am involved -- South Africa before and after the end of the old apartheid regime and (within the context of advanced surgery -- the continuation of a kind of economic apartheid that consigns one population to the category of organ givers -- I hesitate to say donors because not all of the body parts are freely donated -- and organ getters -- again I am avoiding normative medical language throughout so as to break from conventionalized ways of thinking about these body trades.

The Problem:

The need to re- think organ transplant ethics and economics in light of the changes accompanying the social context of transplant surgery as it has moved into new areas where it has been affected by the expansion of global markets in bodies and body parts, including solid organs. Organ transplant takes place today in a transnational space with surgeons, patients, organ donors, recipients, brokers and intermediaries following new paths of capital and technology. The stakes are high, for the practices of transplant surgery have demonstrated their power to re-conceptualize the human body and the relations of body parts to the whole and to the person, and of people and bodies to each other. The spread of these technologies and the artificial needs, scarcities, and new commodities that they inspire raises many issues central to anthropology's concern with global dominations and local resistances including: the re-ordering of relations between individual bodies and the state, between gifts and commodities, between fact and rumor, and between medicine and magic in late and post-modernity.

Background:

The urgent need to define new international ethical standards for human transplant surgery, in light of reports of abuses against the bodies of some of the most socially disadvantaged members of society, brought together in Bellagio, Italy in September 1995 and again in 1996, a small, international group of transplant surgeons, organ procurement specialists, social scientists, and human rights activists. This group, "The Bellagio Task Force on Organ Transplantation, Bodily Integrity, and the International Traffic in Organs", of which I am a member, hammered out a report (published in 1997 in [Transplantation Proceedings](#)) that outlined the dimensions of the problem as we saw it and our recommendations for new legislation and greater surveillance of

organ harvesting and distribution practices.

We focused in particular on vulnerable populations whose "bodily integrity" was at stake: prisoners (living and dead) as reservoirs of spare body parts; the desperately poor, and those caught in the clutches of new forms of debt peonage in which body organs -- bit the kidney in particular -- has begun to emerge as the resource of last resort; and finally -- and here is where I came in -- we tried to unravel the truth if any, behind global rumors of body stealing, child kidnapping, and body mutilations to procure organs for transplant surgery. [my previous work] . The Task Force called -- as most groups of this nature will -- for more research, but of an empirical and ethnographic , anthropological kind, able to pierce the powerful ideologies, rhetorics, secrecy, and hegemony that transplant surgery commands in most parts of the world.

Since Bellagio, my colleague Lawrence Cohen and I, symbolically backed by the now disbanded Task Force, and with financial support from the Open Society Foundation and, more recently, with support from this university, we have initiated ethnographic research in a few sites -- initially Brazil, South Africa, and India -- each chosen because transplant surgery is currently a contentious issue there -- but soon to include new sites in Cuba, Argentina, and Eastern Europe (and through collaborations with David and Sheila Rothman of Columbia University) in the US and Southeast Asia. [Organs Watch]

I chose South Africa as an initial research site for several reasons. I had some previous familiarity with the country (having taught at the U of Cape Town and at the Medical School during the transitional year of 1993-1994 and been conducting research on political violence and its aftermath which put me into contact with surgeons, ER nurses, and pathologists and coroners at the police mortuary in Cape Town. I already had a sense of the problem , a kind of peripheral research vision, regarding the mis- treatment of poor, black bodies then accumulating in great numbers (during 1994-5) at the state mortuary. But South Africa was also of considerable interest because of the country's privileged position in the history of transplant surgery. There was also the question of the radical re-organization of public medicine under the new democracy and the channeling of state funds away from tertiary care and complex medicine toward primary care. This has initiated a transfer of dialysis and transplant surgery into the private sector with predictable negative consequences in terms of social equity .

Although to date most of my research is located in Brazil and South Africa, virtually every site of transplant surgery is in some sense tied to global networks and exchanges. Indeed, one could start from almost anywhere and find one's local study site embedded in complex loops of regional and trans-national exchange.

Field work in South Africa took place between 1998 -1999 during two brief field trips (each roughly six-8 weeks duration) in Cape Town, Johannesburg, Soweto, Pretoria and their rural surrounds. At each site (as in Brazil) I was aided by local research assistants and anthropologist-colleagues. Observations and interviews were conducted at public and private transplant clinics and dialysis centers, medical reserach laboratories, eye banks, public morgues, Intensive Care Units, police stations, newspaper offices, legal chambers and courts, state and municipal offices, parliament and any other sites where organ harvesting and transplant surgery were transacted, discussed or debated. In addition to open-ended interviews with transplant surgeons, transplant co-ordinators, nurses, hospital administrators, research scientists, bio-ethicists, transplant activists, transplant patients patients and living donors (related and unrelated) in each of these sites, I also spent time in rural areas and in urban slums, townships, and shantytowns located in proximity to large public hospitals and medical centers in order to discover what poor and socially marginalized people imagined and thought about organ transplantation, and about the organization of the body, the symbolic and cultural meanings of

body parts, blood, death, and the proper treatment of the dead body.

Ethical Issues in Transplant

The particular ethical issues of transplant today concern:

Living Donation - bone marrow, 1 kidney, half a liver, a cornea and the ethics of both **related** (degrees of relation) and **unrelated** living donation.

Brain Death - Emergence of new critiques and new anxieties

Harvesting of Organs - Issues related to consent, in addition to medical practices related to harvesting - the maintenance of respect for the dignity and integrity of the person that was and who is now designated a non-person, a reservoir of spare parts. As social anthropologists we would include a concern for a larger social ethics that would include for example, a concern for the **Rights of Individuals, Families, Communities vs. the Right of the State** to the disposal and use of bodies and body parts under Presumed Consent Laws (Spain, Austria, Brussels, Brazil] .

Distribution of Organs - social justice concerns - fairness , equity - and rationing of care

Commercialization and Commodification of Organs - Organ sales

Bio-Piracy and Property Rights and the Body - Medical Experimentation without consent (genetic materials through "organ theft") Another subset of issues here concerns State and Police Mortuary Practices to service transplantation, as well as Bio-tech Commercial and Pharmaceutical needs

At a recent grand rounds (September 1999) on Medical Ethics in Transplant by the Chief of Transplant Surgery at UCSF, Professor Joseph Roberts outlined the four basic principles underlying the practical ethics of medical practice, and transplantation in particular as:

-- **Autonomy** - implying a respect for autonomy implies a respect for the person's decisions. 'Every human being of adult years and sound mind has the right to determine what should be done with his own body'

-- **Non-Maleficence** - "Primum Non Nocere" - Above all, Do No Harm. The net effect of any medical intervention should be beneficial. Living donation does harm to the body of the altruistic donor but the social, psychological (and increasingly today the economic) benefits that accrue to the living donor are great and, meanwhile, the tx patient presumably gets better. Consequently, the net effect is beneficial. Problems can arise later - ill effects on the donor and/or when the recipient "rejects" the organ and dies. [encounter family members, particularly in Brazil, who equate the rejection of their organ with personal rejection, multiplying the negative effects of the loss].

-- **Beneficence** the moral duty to promote good acts above and beyond the mere call of duty. Beneficence can demand heroism at times (ex: living donation - bone marrow donation) How much risk should we allow people to engage in for the social good?

How much heroism can a powerful profession like medicine allow? The recent case of the father, a prisoner, of a n Oakland teenager who offered his second kidney to his daughter after

she had rejected the first kidney.

-- **Justice** : Primarily a concern with distributive justice. Here the question of the establishment of regional and national registries, waiting lists, various kinds of monitoring systems can into play to make sure that not only the rich, the beautiful, the white and the famous get the organs they need.

The distribution of scarce organs may be guide, depending on local context, by two contrasting philosophies - - "Battlefield Triage" (save the salvageable first - e.g. the women of the Alto do Cruzeiro toward their infants) vs. Peace Time Triage (assuming sufficient resources , save the sickest first). But in practice both of these are often replaced by a **marketplace triage** - save those , not only who can cover their medical expenses but who can afford the expense of follow-up care - for life which is much more expensive than the transplant itself. Both Cohen and I have found that the scarcest of all commodities in these exchanges is not the organs but patients of sufficient means to pay the top price for the surgery.

Obviously lacking in this limited, highly circumscribed set of medical, bio-ethical concerns and principles is any sensitivity to the social body and to the body politic -- macro- economics, social epidemiology -- let alone, any attention to the actual lived experiences and social and medical realities of particular social groups, classes and populations very different from the the population of transplant doctors and their mostly relatively affluent patients. In all, medical bio-ethics tends to be infused with an individualist, rational choice, utilitarian, pragmatic perspective -- one that is blind to the radically different understandings of the person and the body and very different ways in which people live and the ways they die, especially in what we used to call "non-western" world.

Can we presume that such western, Enlightenment notions as bodily integrity and autonomy are universally shared? What does the ownership of the body mean in spaces (like plantation society NE Brazil where centuries of debt peonage have made people begin to think of their organs as their last resource. Or what does "ownership" of the body mean in a rural Xhosa society still contained within a collectivist ethos that understands the body as the property of "the ancestors"?

What, after all , is an Organ? asks Veena Das?

What is a Death? asks Margaret Lock?

What is a life? Cohen and I have asked

[the powerful rhetoric around scarcity, need, gift, donation -- all need to be deconstructed]

Anthropology -- which Max Gluckman , once described as "the study of oddments by eccentrics" -- is ideally positioned to examine the changes that have occurred in the once highly elite and esoteric practice of organ transplant as it has moved into new areas of the world , in new social and economic and cultural contexts, where new scarcities, desires, needs, interact with very different conceptions of justice, fairness and moral goodness and rightness. Our particular spatial positioning -- neither unambiguously "local" nor obviously "global" -- but somewhere on a scale in-between -- gives us an intellectual and methodological tool kit that allows us to conduct a multi-sited study of a small but rapidly expanding technology and practice of advanced medicine. And, it is anthropology's marginal and liminal nature, its lack of worldliness and conventional forms of power and prestige, that allow us to disarm and penetrate what is a very secret world. Various national societies of transplant surgeons remind me of nothing so much as a traditional west African secret society. Medical doctors, let alone, surgeons

are rarely threatened -- at least initially -- by anthropologists, and we are often seen as benign and amusing sorts of fellows. Every operating room, like every Navajo family, ought to have one -- preferably in drag - draped in mimetic native attire, be they surgical robes or Navajo fancy shawls.

The South African example exemplifies many of the ethical and economic quandries and conflicts and contradictions resulting from the globalization of transplant surgery -- especially the increased movement and circulation of tx patients, surgeons, bodies and body parts, commercialization of body parts, the impact of economic structural adjustments, , reduction of state support for tertiary care, medical research, and transfer of state support to primary care and the emergence of large for profit medical corporations like NET CARE, and the consequent privatization of advanced surgery, including even dialysis.

One of the key paradoxes of the new South Africa is that it is heroically trying to construct a modernist nation-state under both pre-and post-modern conditions. I refer, on the one hand, to the global economy which continually interrupts the ideals enshrined in the new constitution , and on the other hand, I refer to the pauperization of rural areas , to an urgent sense of relative deprivation in a society beset by mundane, everyday first world-third world juxtapositions - and to the nervous collapse of some major urban centers , like down town JB leading not only and inevitably to social epidemics of violent crime but to outbreaks of witchcraft hysterias and to new forms of magic and mysticism ("new magic for new ends"). Transplant surgery and the new forms of body magic have in recent times intersected.

The Generative Narrative

The way Dr. DeNobrega, a self-described second generation Cape Town heart transplant surgeon , now retired to his extensive wine producing estate near Stellenbosh tells it, "Well, it was a stroke of luck, really. She was a young girl of about 25 and she was going out with her father to a birthday party. The pair had just stepped out of the bakery with the cake and they were crossing Main Road to get back to their car. But they never made it; in the middle of the road they were hit by a truck and knocked to smithereens. Luckily for us, the emergency room [of Grotte-Schurr Hospital] was just up the road and the girl was quickly diagnosed with a fatal head injury. There was brain damage and Chris Barnard was right there waiting in the wings. He claimed the unlucky girl as South Africa's first organ donor. " The young woman, as almost any white South African can tell you, was Miss Denise Ann Darvall -- and the man whose luck it was to receive her heart was Luis Washkansky. A week later the scrappy doctor from South Africa was a phenonenon, featured on the cover of [Time](#) magazine.

This was in December 1967 and the world held its breath during the 18 days that Mr. Washkansky clung to his new life before he died. Nonetheless, Chris Barnard and his team claimed the operation as a success. It was not Miss Darvall's heart, they said, that had killed the first transplant patient, but a bilateral pneumonia. Encouraged and emboldened , the transplant team at Grotte Schuur performed another operation less than a month later. This time a 50 year old dentist, Dr. Philip Blaiberg got his new heart from a young colored (mixed race) man, Clive Haupt, who had collapsed on a Cape Town beach on New Year's Day in 1968. "Dr. Blaiberg was a much better candidate for transplant", said deNobrega. "and he lived for a full year. After that, the ball really started to roll, and the Grotte -Schuur team performed several more transplants before the rest of the world started catching up with us. Your man, Shumway, at Stanford University was very very unhappy to have been upstaged by our Chris Barnard. Here in South

Africa, a pariah nation, we were making medical history!"

So, the origin myth begins with a brash young South African physician and medical professor at the University of Cape Town, Christian Barnard, who transgressed conventional medical norms to make heart transplant possible. In the words of Barnard's admiring protégé, Dr. De Norbrega: "No, they didn't exactly break the rules, they were learning the rules, for the first time...But he [Barnard] was totally impossible, totally impossible. When he goes to heaven, they're going to judge him by a different set of rules altogether because he was impossible to work for, but he was a front runner and he was so far ahead, and everybody else was so busy catching up trying to be in his shadow, which is where I consider myself, as a second generation cardiac surgeon. He and his team made mistakes, they took risks they perhaps should not have taken, they were utterly and completely arrogant, but they also had honesty, they had intellectual integrity, and they had courage and enormous motivation". Times have changed, and since that time no one knows, let alone, memorializes the names of the next succession of organ donors who quickly receded into an invisible population of "anonymous" heart beating cadavers. Nor, to be fair, does anyone recall the names of the heart recipients, except for the occasional celebrity. Heart transplant surgery soon settled down into a routine and normative procedure. The personalism and the heroics has long since given way to a certain growing resentment and restiveness among the younger generations of heart transplant surgeons, and in the general populations of potential organ donors in South Africa -- white, black, and mixed race.

In Cape Town, for example, the scramble for scarce hearts following the opening of the first for profit heart transplant unit at downtown City Park Hospital led to acrimony between state and private transplant units and to accusations and counter-accusations between the directors of each unit. My visit with Dr. DeNobrega on that particular sunny Sunday afternoon in February 1998 was occasioned by a law suit I was attending in the Municipal Court of Cape Town (Vossloo v. Von Oppell) at which imminent heart surgeons from both public and private sectors were taking the dock to accuse each other of defamation of character, concealing and destroying viable donor hearts, and suppressing statistics showing an excess run of unaccounted for mortalities in recent heart transplants. Surgeons in the public sector blamed the insufficient training of the new surgeons practicing in the private sector, while private surgeons argued that standards were falling miserably in the now under-funded public sector, provincial hospitals. Both claimed that the greed and envy of the other was at the source of the law suit. Finally, the case ended up in the Municipal Supreme Court of Cape Town with a stinging reprimand from the judge against both parties, ordering them to go home and clean up their acts.

Dr. Johan Brink, a third generation heart transplant surgeon at G-S Hospital, shared during an interview in 1998 that he had become very "*disheartened*" about his profession's decline in prestige, trust, and in value: "In my view organ transplantation has moved from an era back in 1967 when the atmosphere and attitude was very different...People still spoke about organ donation as that fantastic gift. Our first organ donor, Denise Darvall and her family were very much hallowed here. They were given a lot of credit for what they did, and their photos are displayed in our hospital's new Transplant Museum. Society at that stage was still very positive. Now that there have been thousands of donors throughout the world the idea of organ donation has lost some of its glamour. Donor families have been put under a lot more pressure. And there have been some unfortunate incidents... So, all of a sudden we are beginning to experience a sea of backlash. This is entirely new for us."

Meanwhile, a stone's throw from the famous Groote-Schurr teaching hospital where Christian Barnard pioneered heart transplants, Africans in the Black townships outside

Cape Town often express fearful, suspicious, and negative attitudes toward organ transplantation. Among older people and recent residents from the rural homelands, the very idea of body tampering and organ harvesting around death bears an uncanny resemblance to traditional practices of "muti" (magical medicines) and the removal of body parts -- especially skulls, hearts, eyes, and genitals -- which are sold and used by deviant practitioners (sangomas) to increase the wealth, influence, health or fertility of a paying client. In 1998 an older Xhosa woman and recent rural migrant to the outskirts of Cape Town responded in disbelief when I first confronted with the facts of transplant surgery: "If what you are saying is true, that white doctors can take the beating heart from one person who is dead, but not truly dead, and put it inside another person to give him strength and life, then these doctors are witches just like our own".

Meanwhile, and thickening an already complicating the plot, witchcraft and other magical practices -- many of these relating to the use and abuse of animal and human body parts, have increased in both rural and urban areas following the transition to democracy (see Comaroff and Comaroff 1999, in press). These gargoyles of the past testify to the "modernity of witchcraft " (Geschiere 1997) and to the longings and heightened and "magical" expectations of poor South Africans' for improved life chances and material comforts since the fall of apartheid and the election of President Mandela. Long-frustrated desires for land, employment, housing, and a fair share in the wealth flaunted by whites, and the radical improvements promised but not yet delivered through various neo-liberal development programs such as the World Bank's funding of a macro-economic development scheme called GEAR have fostered a resurgence of traditional and modern forms of magic.

In 1995 an angry crowd in Nyanga township in Cape Town tore down the shack of a suspected muti-murderer after police, tipped off by a local informer, discovered the body parts of a missing five-year-old boy, Lucky, smoldering in the fireplace and stored in medicine jars and boxes in the suspect's shack. On June 8, 1995, Moses Mokgethi was sentenced in the Rand Supreme Court, Gauteng, to life imprisonment for the murder of six children between the age of four and nine. Mokgethi claimed he mutilated the children and sold their hearts, livers and penises for 2,000 to 3,000 rands each to a local township businessman who hoped their purchase would strengthen his business. Such incidents reported in daily newspapers are often followed by anxious rumors of luxury cars prowling squatter camps in search of children to steal for their heads and soft skulls or rumors of body parts stolen by witch doctors from public morgues, or sold to them by morgue employees for use in rituals of magical increase.

In Johannesburg in April 29, 1996 a 38 year old man was arrested in a shopping mall after he was caught "trying to sell a pair of blue eyes". The city's largest newspaper, *The Star* reported that the incident " might be linked to the murder of street children for...traditional medicines". The story continued noting that body parts were traditionally and still used in potions for fertility, success in business, and for luck in love. The organs and body parts of white children commanded the highest prices.

White Bodies, Black Hearts

Race has always been at issue from the beginning of South Africa's organ transplant program. And it continues to haunt the practices of transplant surgery to this day, the democratic transition notwithstanding.

Chris Barnard may have been a rebel and an arrogant son of a bitch, but according to his former colleagues and followers he was equally casual toward the harvesting of organs from black and white South Africans. They insist that Barnard was no racist. But nor was he color blind and he knew -- if he wanted his fledgling program to survive -- that the first organ donor at least, should not be Black or coloured, so as not to upset the absurd canons of apartheid racial purity. As Dr. Johan Brink put it: "Chris was one of those people who was arrogant enough to ignore the government. Even when our hospital wards were still fully segregated by law, there was no 'race apartheid' in transplant surgery." [Below I will explain what Brink meant by this].

When Dr. Blaiberg received his heart from Clive Haupt, it was a bold and dramatically symbolic move -- the heart of a colored man continued to live and to beat in the breast of a white man in a country where blood banks still kept coloured/ black and white blood restricted to racial group. Reservations were expressed by both whites and blacks in South Africa and beyond. The Deputy Foreign Minister of Uganda, for example, was fearful that this operation would begin a process of transforming black Africans into "spare parts for whites". Blacks were hardly regarded as humans in South Africa, though now their hearts will suddenly become a precious commodity for whites.

I often heard similar fears expressed by township residents outside Cape Town and in Soweto. Younger township residents who are knowledgeable about organ transplantation tend to be highly critical of the practice as part of South Africa's legacy of apartheid medicine. "Why is it," I was often asked, "that in our township we have never met or even heard of such a person who received a new heart, or eyes, or a kidney? And yet we know a great many people who say that the bodies of their dead have been tampered with in the police morgues?" Township residents are quick to note the inequality of the exchanges in which organs and tissues have been taken from young, productive, black bodies—the victims of violence caused in large part by substandard housing, poor street lighting, bad sanitation, and hazardous public transportation, and political violence inherent to apartheid and the black struggle for freedom—and transplanted to older, affluent, debilitated, white bodies. In their view, organ transplantation reproduces the notorious Body of Apartheid.

There is some truth to those allegations. During the heyday of apartheid, transplant surgeons were not obligated by law to solicit family consent before harvesting organs (and tissues) from cadaveric donors. "Up until 1983 or 1984 the conditions for transplantation were easier," said Dr. Brink, the cardiac surgeon from G-S Hospital. "We didn't worry too much in those early days. We just took the hearts we needed, but it was never really a racial issue. [Chris Barnard was very firm about this. He was one of those people who was arrogant enough to just ignore the government.] Even when our hospital wards were still segregated by law, there was no 'race apartheid' in transplant surgery." But what Dr. A meant was that there was no hesitancy on the part of doctors in transplanting Black and Colored (mixed race) hearts -- sometimes taken without the consent or knowledge of family members -- into the ailing bodies of their mostly white, male patients. (Until the early 1990s 85 percent of South Africa's heart transplant recipients were white males). Surgeons refused to reveal the race of donor hearts to concerned and sometimes-racist organ recipients, saying that hearts have no race. "We always used whatever hearts we could get", Dr. A said, whether or not the patient feared he might be getting an "inferior" organ.

With South Africa's passage of the Human Tissue Act of 1983, the donor or family must give prior consent and organ harvesting immediately became more complicated. South African Blacks have been reluctant organ donors while members of the large Cape Malay

Moslem community will accept donor organs but refuse to be organ donors themselves due to perceived religious prohibitions.

When asked why until post 1994 there were so few Black and mixed-race heart transplant patients, Dr. B referred to medical research had indicated that "Black South Africans coming from rural areas did not suffer the modern, urban and stress-related scourges of ischemic heart disease which primarily affects more affluent white males in urban settings." (I believe the source was a medical anthropological study from the 1950s). This medical just-so story would be hard to reconcile with the reality of South African Blacks and Coloreds who were subjected throughout apartheid to forced migration to mines and other industries in the Gauteng peri-urban area, and to forced removals to urban squatter camps, worker hostels, and other highly stressful urban institutions. In the Western Cape region, where Groote-Schurr Hospital is located, 89.9 percent of the population is urban. In Gauteng, where Johannesburg and the second-largest center of organ transplantation is located, 96.4 percent of the population is urban. It was also difficult for the doctor to explain why, following the democratic transition, there was, in fact, an almost immediate democratization of heart transplant surgery at the public, academic hospital. In 1994, the year of the elections, for the first time a significant percentage, 36 percent, of all heart transplant patients at Groote-Schurr hospital were assigned to mixed-race, Indian, or Black patients.

At present, organ transplantation is moving rapidly from the state, public-sector hospitals and the academic research centers where transplantation was first developed in South Africa to new, relatively autonomous, private, for-profit hospitals.

Soon only the wealthy and those with private medical insurance will have access to transplantation. In November 1997, the highest court in the new South Africa, Constitutional Court, decided against a universal right to state funded dialysis and kidney transplantation. The court was responding to the case of a 41-year-old unemployed man from Durban who is a diabetic with kidney failure. The Durban man had used up his available medical insurance and was denied dialysis at public expense at the provincial hospital, after suffering a stroke. The high court upheld the South African Ministry of Health's policy based on the new nation's limited financial and medical resources. **And so, Mr. Soobramoney** was sent home to die.

At the Baragwanath Hospital in Soweto kidney transplants were suspended beginning in 1994 and all state supported transplants moved to Johannesburg general hospital. Since that time only a miniscule number of Sowetans attending the Bara dialysis clinic have been called for transplant, and during my last visit in 1999 I attended hospital bedside rounds during which several dialysis patients were terminated.

From The Bargwath Hospital I went to Medunsa Medical School which, I was told, had a viable kidney transplant unit and an able transplant co-ordinator named Sister Ndlovo. Sister Ndlovo explained, however, that only living kidney donors were used.

She explained: " : I prefer to work with the living donors. ... We have a nice prof who heads the ICU but his manner of referring is not up to par. If I follow his ways I'll be destroying my own future. He'll say, Sister, we have a brain dead person, he'll say, 'he's a good guy; he's brain dead. Proceed. Take him.'" And I would say, "Prof, I can't proceed with this. I'm destroying my name. We really need a doctor who will check the chart on this person."

"Are you saying that this doctor is not performing the proper tests?"

"That is right. As the head of the unit , he just says 'This one here is brain-dead'. But there are no tests and now there is nothing that is written down. And I need it in papers.

"You have to educate him about the proper procedures."

"Oh, he will say, I know what they are. You see, he is the one in charge and he will just say , ' well, this is how I do it. If you want it, take it, if you don't want it, it is up to you. But don't bother me with the tests and the paperwork' This man is the head of the ICU and he is the one who is retarding our progress here. He is very aware of the protocol but he feels that he cannot waste the resources to do all the brain tests, or to talk to the families, because actually most of them will just say no in any case. So, he says, don't bother me just take the ones, the brain dead somebodies, I indicate. But that will ruin my unit. "

Sister Pat, a retired transplant co-ordinator from Cape Town , later commented on this rather startling transplant "anecdote" which I shared with her without revealing any of the particulars. She said:

" Unfortunately, this kind of thing is not uncommon. These old guard doctors are never going to admit the truth, which is that they really don't know how to do the brain death test. So they say : 'We haven't got the money or the resources. I had a hospital superintendent once who phone me to say that they had a potential child donor and could he bring her into our [private hospital] pediatric ICU where I was working. So I said, 'Doctor, please tell me a bit about the child.' So, he told me she had a serious head injury. So, I said what is the child's (Gredsko-Coma??) scale. You know what it is? [No] Well, it's just a number that you assign on the basis of a simple test...and whether the person opens their eyes or speaks or presses your hand or whatever. I felt so sorry for him, beca use he mumbles to me on the phone , 'Well, I don't know about that because we haven't got that expensive machinery over here. And it's just a simple clinical test. You don't need any machinery at all. But these types are not going to admit that they don't know how to do something, and they are never going to find out how to do it either. It's a form of laziness."

Conditional Donation

In the absence of a national policy regulating transplant surgery, and no regional, let alone national, official waiting lists, the harvesting and distribution of transplantable organs is left largely to transplant surgeons and to the very small number of transplant co-ordinators working in public, but increasingly, in private hospitals and affiliated with Netcare. [Netcare manages some 35 private hospitals and day clinics in South Africa's largest cities. After the for-profit conglomerate aquired its competitor, Clinic Holdings Ltd. in 1997, Netcare became the largest private hospital network and hospital group conducting organ transplants on the African continent.

Although all academic medical centers have ethics boards to oversee decisions about the harvesting and distribution of organs, in general, transplant teams are allowed a great deal of autonomy in their decision making. Public and private hospitals hire their own transplant co-ordinators who say they are sometimes under pressure from competing, even warring, factions to drop the usable heart or kidney in a bucket rather than give it to a competitor. In the current climate of privatization there is considerable room for the corruption of informal waiting lists.

As explained to me by the new transplant co-ordinator for an emerging Organs Procurement Trust for Gauteng, the dilemmas is that when an organ is matched to a patent

from hospital X, his doctor is responsible for seeing whether the assigned patient is, in fact, in medical conditions to receive it. If not, the doctor will ask to assign the organ to another of his patients who is a "better" match. [Inbetween the lines the story suggested that the doctor can manipulate the list internally once he has been advised that the organ is "his". So, one way of putting it -- (as Andy Lakoff noted yesterday) is that in reality it is the doctors and not the patients who are on the waiting list! [Similar situation exists in Brazil]

Finally, a new harvesting and allocation dilemma has arisen , since the democratic transition, to subvert the democratic principles enshired in the new Constitution and in the emerging concept of standardized and monitored regional waiting lists: the practice of conditional donation. Since the passage of the 1983 Organs Act in South Africa which requires prior or family consent to donation, organs that were once readily available in the early stages of transplant, suddenly became very scarce commodities, indeed. Freely donated organs tended to come from lower middle class whites. During apartheid when the trust of this population group in the academic hospitals was strong, donation rates were high. Donor families never bothered to ask who the recipients would be, as they assumed their precious organs or those of their loved ones would go into bodies similar to their own.

Today the provincial (state) hospitals are thoroughly democratized and the public tx surgeons are seen as catering to the bodies of 'the other'. Hence, the subterfuge of race-indicated donation. Since Black and Muslim Coloured South Africans have been slow to donate, the phenomenon concerns white South Africans requesting that their organs be donated to other whites. What appears as a philosophical conundrum to Dr. Kerresault and Dr. Konig in Pretoria, appeared in her lap as a life and death decision for the transplant co-ordinators. Here is how one tx co-ordinator handled such a demand:

" A transplant coordinator phoned me from Durban to say that she had a donor and I said after looking at my list, , 'yes, I can use the heart and I can use a kidney'. And she hemmed and hawed about the kidney but finally she agreed. We got the heart that night and I was very busy obviously because I had to get the patient prepared and get the heart and all. ... So, later, I phoned the Durban coordinator and I said the transplant went very well. Then the doctor who went out to harvest the kidney, phoned me after the heart transplant and she said " I wasn't going to tell you this , but the kidney I was going to use wasn't going to work., and that it was a case of conditional consent –only goes to whites.

Now that's the first time I had heard anything about it being conditional. And I said, ' Oh my God help me... it would have been too late to stop that heart transplant, but it had gone to a white man in any case. But the one who I was going to give the second kidney to was a colored man. Why was it conditional? Well, there was a whole long story about the family member had been killed by blacks which all turned out to be phoney, a lot of lies.

So I now here I sat with this kidney. So I phoned up [two local provincial hospitals] and I told each one that I had a kidney, conditional consent, and my heart just bled. Both the kidney transplant heads at [Hospital A] and at [Hospital B] are Indian gentleman. And I said, I've got this kidney but I am embarrassed to say it's a conditional consent. But I said, please accept it anyway. Don't put it to waste. I know you'll find a recipient for it. And I said I had to apologize for putting them into this. They said, alright , leave it with us and we'll discuss it. They each had a meeting at their hospitls. It went right up to superintendent, professors, you name it. They called everybody up for the meeting and they turned around to me and they **said to me the answer is no...**they will not use the kidney. They said we discussed it all amongst ourselves and

we took a vote and this was amongst white doctors, Indian doctors and black doctors, you name it. Whoever was on the staff. The vote was they were not prepared to use a donor from a conditional consent.

So, I went back to the family through the original coordinator and I asked would they change their mind. That's when she gave me this whole long story about the killings, some whole long rubbish story that I didn't care to hear about. Then I sat there with this bloody kidney on my hands. And the time was running out. Eventually, the

co-ordinator in Durban called asked that the kidney be sent back to them immediately, they had found their own donor....So, now they were going to take this kidney and put it into a white man in Durban! And the poor man in Durban isn't going to know himself until after the transplant that this was a conditional consent. He might have grave doubts about taking a kidney under those conditions. And if this hit the newspapers the story might kill transplants in this country altogether.And I sat there and you know I hadn't had sleep for 36 hours and they phoned me from J'Burg and they said to get that kidney on the plane now. On the way to the airport I phoned them all on the cell phone and I said...I can't do it... And they turned around to me and said, it's your decision, you're the coordinator, you've got the kidney.... But I tell you, it was not easy. I sat there and I didn't know what to do. I got as far as the airport and then I took that kidney, wrapped it up, and I just threw it away. I did it! I put the kidney into the dumpster! And I had no idea whether this was the right thing to do or the wrong thing to do, but let me tell you, I got into so much trouble from J'Burg and Durban. Oh, absolutely! I didn't get to bed for another 24 hours because of the abusive phone calls. But I went to sleep feeling relieved."

Living Donation and The Emergence of Organ Sales

Meanwhile, the temptation to accommodate private and foreign patients who are able to pay the full market cost of heart and kidney transplant is affecting both the public and private sector hospitals. At Groote-Schurr's kidney transplant unit, a steady trickle of donor couples arrive from Mauritius and Namibia. Although they claim to be related, the nurses say that many are simply paid donors, but since they arrive from across the border, the doctors look the other way. While I was in Cape Town in 1997 an ill older business man from the Cameroon's with end stage renal disease arrived at the kidney transplant unit with a paid donor the man found in Johannesburg. The donor was a young university student from Burundi who agreed to part with one of his kidneys for his expenses and a bonus of \$2,000. The head of the kidney unit read the international medical codes against organ sales to the pair, explained the risks and dangers of living kidney donation, but as they persisted he agreed to order the blood matching tests. When they failed to match and were turned away, the symbiotic pair begged to be transplanted in any case. Such was their almost unimaginable desperation, that they were willing to face the eventuality of almost certain organ rejection. Of course, the doctors refused their plea. Of course, the question is whether private hospitals will be as conscientious as the public ones in refusing hopeless cases among those patients willing to pay regardless of the outcome?

But for those who live at a distance, without easy means of communication and transportation, such as in the sprawling townships of Soweto outside Johannesburg and Khayalitsha outside Cape Town have a ghost of a chance of receiving a transplant. The rule of thumb among heart and kidney transplant surgeons in Johannesburg is: "No fixed home, no phone, no organ."

The ironies are striking. At the famous Chris Hani Bara Hospital on the outskirts of

Soweto, I met a sprightly and playful middle-aged man, flirting with nurses during his dialysis treatment. "He's very familiar with you!" I commented to the head nurse. "And well, he might be," she replied. "He's been on the waiting list for a kidney for more than 20 years." Not a single patient at the huge Bara Hospital's kidney unit had received a transplant in the past year.

An exception to this rule was a portly, middle aged man, whom I chanced to meet in the dialysis clinic at the at the sprawling Baragwanath Hospital in Soweto. Simon got his kidney a few years ago at the Bara by sheer luck.

[fill in]

The week before I was in the splendid, suburban community of Sun Valley outside Cape Town where, in a private, gated community protected by armed guards for the comfort and security of the wealthy, white, and mostly retired residents, I met with Mr. Wynand Breytanbach, ex-deputy minister of defense under President P.W. Botha. Breytanbach was recuperating from the heart transplant he had received on his government pension and health plan following less than a month's wait. A hospital nurse reported that at first he was distraught to learn that he was the recipient of the heart of a young, mixed race nurse. And he blamed his initial difficulties on his "inferior woman's heart." He has since softened. He told me that he is extremely grateful for the woman's sacrifice and that he has tried to contact the family of his donor through the hospital network to express his thanks. The family has not responded.

As we chatted about his time served on the old South Africa's notoriously violent Security Committee, I had to control my rising sense of outrage.

This prompted me, finally, to ask Mr. Breytanbach if he thought he owed the new South African government something for having given him, of all people, a new lease on life. He replied: "To this day I still do not know why I was given a heart transplant. I know that at the time I had only 10 or 12 days at most to live and if I did not have [the operation] I would be dead. And it is great to be alive! I look at the country and I see that there may be more people more deserving than me of a heart transplant, and many who cannot get it because of a shortage of funds or of donors with so many people waiting for hearts." Meanwhile, at the venerable Groote-Schurr Hospital a virtual moratorium had brought heart transplantation to a standstill.

Windows of the Soul

Meanwhile, at the Cape Town state-run police mortuary, I investigated allegations by Black township residents of the misuse of body parts related to transplant surgery and to "muti" medicine. The published reports of the South African Truth and Reconciliation Commission have brought to light the collaborations of a great many physicians, district surgeons, and state pathologists (during the worst phases of apartheid) working at the state run mortuaries in covering up police actions that resulted in deaths and body mutilations of hundreds of "suspected terrorists" and political prisoners. Consequently, to this day, the police morgues remain places of horror and suspicion to many residents of South Africa's townships.

Rumors of body tampering have been augmented by reports by journalists. On July 23 1995, the Afrikaans newspaper, *Rapport*, reported that a private detective testified in Johannesburg Regional Court that a policeman showed him the mutilated body of Black

activist and political hero Chris Hanu in a Johannesburg state mortuary one day after he was murdered in 1993. During an investigation a human heart alleged to be that of Hanu's was sold by a minor official to investigative reporters for 2,000 rand. The heart was subsequently handed over to the police.

In the course of my investigations in 1993-4, 1996, and again in 1998, I learned that cornea, heart valves, and other human tissues were routinely harvested by state pathologists and other mortuary staff and distributed to surgical and medical units usually without asking the consent of family members. The 'donor' bodies, most of them township Blacks and Coloreds, who were victims of violence and other traumas, are handled by state pathologists attached to public mortuaries still controlled by the police. Some pathologists hold that these practices are legal, but some of their colleagues consider them unethical.

[Dr. Zilla - and the contract to supply to medical centers in Germany and Austria heart valves taken without consent from black bodies presumed unidentifiable from the Salt River Mortuary]

[transparency]

A junior state pathologist at a prestigious academic teaching hospital talked of his uneasiness over the informal practice of "presumed consent." A loophole in the 1983 Organ and Tissue Act allows "appropriate" officials to remove needed organs and tissues without consent when "reasonable attempts" to locate the potential donor's next of kin have failed. Since eyes and heart valves need to be removed within hours of death and given the difficulty of locating families living in distant townships and squatter settlements without adequate transportation and communication systems, some doctors and coroners use their authority to harvest the prized organs without giving much thought to the feelings of the next of kin.

The doctors justify their actions as motivated by the altruistic desire to "save lives." In return these organ providers gain, minimally, the gratitude, professional friendship, and the respect of the prestigious transplant teams who owe them favors in return. Since harvested cornea and heart valves are sold to the hospitals and clinics—domestically and in the case of heart valves internationally—that request them, the possibility of secret gratuities and honoraria paid on the side to cooperating mortuary staff cannot be discounted. Small gratuities were paid, for example, by a local independent eye bank to transplant coordinators for the favor of carrying donor eyes designated for air transport to the local airport.

There is an active debate among pathologists, forensic specialists, lawyers, bio-ethicists, and theologians about current mortuary-to-surgery practices which are sometimes deemed unethical or worse. Currently, the South African Truth and Reconciliation Commission is considering allegations of gross human rights violations by the parents and survivors of 17-year-old Andrew Sitsheshe. Mrs. Rosemary Sitsheshe and her relations want their son's case to draw attention to what were under apartheid -- and what may continue to be -- routine violations of the mostly Black and poor bodies carried to police mortuaries

According to Mrs. Sitsheshe, whom my field assistant Monga Melwani and I interviewed in Cape Town in 1998 and again last summer in 1999, she is still unhappy, angry, and unresolved about what happened to her son. According to her personal testimony, there was really much more at stake than the theft without consent Andrew's eyes by the Salt

River mortuary staff. But for the sake of her public testimony to the TRC that is what her lawyers and representatives focused on.

In brief, on a Saturday night in August 1992, 17 year old Andrew Sitshetshe had gone to a men's hostel a few blocks from his home in Guguletu township. He went to collect payment for a radio he had repaired for a resident of the hostel, but on arriving there he was caught in the line of fire among members of the township's Balaclava Gang. Andrew was shot in the chest and was taken to the Guguletu police station. His mother, Rosemary, who heard the shots and was notified by neighbors, rushed to the police station where she found her son lying on the floor with a bleeding chest wound. She identified herself and her son to the police officers. Andrew's eyes opened and closed and he tried to raise his hand to his mother. But by the time the ambulance arrived, after an interminable delay [usual for the emergency response to a nearby township like this] the police sent Mrs. Sitshe home, saying that Andrew was dead.

In a state of shock and grief, Mrs. Sitsheshe went home sustained by her mother and other relations. The police called the Salt River Mortuary and told his mother she could claim his body on Monday morning at the mortuary, which was closed all day Sunday. That night, however, the state pathologist, who said that he believed the body of Andrew Sitshetshe was "unidentified" and who had no written notice indicating that the deceased would not want to be an eye donor, gave permission for Andrew's eyes to be removed and given to Ms. Room of the South African Eye Bank, a private foundation conveniently located in Lower Observatory in close proximity to both Groote-Schuur Hospital and the SALT River police Mortuary in Cape Town.

When Andrew's parents arrived at the mortuary on Monday morning the police officials there said the body of their son was not yet ready for viewing. They were finally allowed to view the body at 3 p.m. Mrs. Sitshetshe was shocked at the changes she saw in her son's body since she left him at the Guguletu police station. She asked to come behind the glass and to view her son's body from all angles. The mortuary staff resisted at first but then allowed the mother to come close to her son. She said:

'I noticed that the blanket that was covering the body was full of blood; and I discovered that he had two deep holes on the sides of his forehead and you could easily see the bone. His face was in very bad condition. And I could see that something was wrong with his eyes... I started to question the people in charge and they said nothing had happened... '

Mrs Sitshe went to the ANC office and was advised to hire an independent pathologist who later determined that minimally Andrew's eyes were surgically removed and the orbits filled with cotton wool and covered by a pink plastic eye cup in each case. Because of the extensive autopsy many of Andrews organs had been severed and returned to his body cavity. But the pathologist could not confirm if these were , in fact, Andrew's own body parts. The Sitshetshe family returned to confront the staff of the Salt River Mortuary where, they said, were treated abusively. The head state pathologist explained to the parents that it would have been impossible to phone the family, although they owned a telephone and were awake with grief the entire night. Since the pathologist had been able to call the director of the Eye Bank in the middle of the night, why not themselves Andrew's mother asked?

A few days later, Rosemary Sitshetshe , still unable to rest, went to the Eye Bank to confront the director of the Eye Bank who told the mother that her son's corneas already been "shaved" and given to two recipients . She refused to surrender what was left of his

eyes to Andrew's mother for her son's burial. "Although my son is buried", Rosemary contended to the TRC, "is it good that his flesh is here, there, and everywhere, that part and parcel of his body are still floating around?"

She told the TRC Hearings:

"I stand up and condemn this act in the strongest terms and those who are guilty must be punished... Must we be stripped of every comfort as well as our dignity?... How could the medical doctor decide or know what was a priority for us?"

In her formal statement to the TRC in 1997, Leslie London, a professor of health at the University of Cape Town, said, "these were not events involving a few bad apples... Rather, these abuses arose in a context in which the entire fabric of the health sector was permeated by apartheid, and in which human rights were profoundly devalued."

Mrs. Sitshetshe, who in four years was unable to get the attention of the Groote-Schuur ethics committee or the hospital's administrators, has since joined with others in Guguletu township in a campaign to end the unauthorized harvesting of organs of mainly black and poor people in state mortuaries who have died tragic and violent deaths. **The complaints of the Sitshetshe family** toward organ harvesting and transplantation practices are now shared by many others in the poorer townships that I have been visiting since 1994. These feelings may have contributed to Health Minister Dr. N.C. Dlamini Zuma's controversial transfer of public support away from tertiary medicine to primary care, a move not without its own contradictions.

Truth and Transplant

Among the questions raised by the case of Andrew Sitshetshe there is one of central concern to the TRC: how, under the new Bill of Rights, can the government equal access to organ transplantation for all of South Africa's people in need, especially those not covered by medical aid schemes? How can the state institute equitable harvesting and transplantation? The section in the Bill of Rights dealing with bodily integrity specifies "the right of all citizens to make decisions about reproduction and their bodies free from coercion, discrimination and violence." An ANC spokesperson says the inclusion of the words "and their bodies" were meant to refer to organ transplantation in South Africa. Before the TRC there were only rumors and allegations of medical abuses. Following those hearings certain 'wild rumors' are being substantiated as the facts of apartheid medicine.

Recommendations

Except for the 1983 TISSUE ACT and the regulations regarding the registration of private hospitals there is today in South Africa no legislation to monitor and to control the procurement, storage or distribution of organs or the performance of organ transplants. It would seem absolutely essential that the Ministry of Health develop regulations and a policy toward transplant medicine which is the most social and political of all medical practices. Moreover, it is essential that the South African government devise procedures to ensure the cooperation, consultation and coordination of transplant units between the public and private sectors. A national registry to determine the need for organ transplant, the criteria to be used in setting up at least regionally based waiting lists should replace

the ad hoc methods currently in use whereby

individual head surgeons maintain their own lists and consult with transplant co-ordinators attached to individual hospitals, public and private. While the oft expressed desire to "nationalize" South African organs has a mean-spirited and jingoistic feel to it, the intention behind such sentiments is to suppress the growth of transplant tourism, as

affluent foreigners arrive looking for surgeries for which they have been denied at home or because the cost of these surgeries is significantly cheaper in South Africa at the present time. Exceptions to this rule can be written into the transplant guidelines and can require approval and authorization from the Ministry of Health to preserve the general sense of medical beneficence even toward the needy stranger or, "crossborder " patient, as they are called in South African hospitals.

Conclusion:

Organ transplantation depends on a social contract and social trust. This requires national and international laws protecting the rights of both organ donors and organ recipients. At a rudimentary level, the practice of organ transplantation requires a reasonably fair and equitable health care system.

The social ethics of transplant surgery -- which gives precedence to justice over individual autonomy -- also requires a reasonably democratic state in which basic human rights, especially bodily integrity, are protected and guaranteed. Where vestiges of forced labor exist, and where unjust trade in corneas and kidneys, transactions continue to be "legally" and "medically" covered up, the distrust of medicine and transplant surgery will persist.

Under such conditions the most vulnerable will fight back with the only resources they have—gossip, rumors, or rebuttals and resistance to modern laws. In this way, they settle accounts, albeit obliquely and articulate their own ethical categories in the face of the "consuming" demands which value their bodies as a reservoir of spare parts. While a heart is just a pump, a kidney is just a filter to transplant surgeons and to body dealers, ordinary people believe these organs to be something else—a lively, animate, spiritualized part of the self they want to take with them when they die.

About the Author

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