

Bioethics and Human Rights: A Problem, a Proposal, and an Achievement

Author: Gabriel J Pleasants

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Introduction: Two Models of Bioethics

We thus find ourselves at a crossroads: health care can be considered a commodity to be sold, or it can be considered a basic social right. It cannot comfortably be considered both at the same time. This, I believe, is the great drama of medicine at the start of this century. And this is the choice before all people of faith and good will in these dangerous times.

Paul Farmer¹

How and why, in this age of extraordinary wealth and technological advancement, do people routinely suffer and die from preventable and easily treatable diseases?

Jim Yong Kim, Joyce V. Millen, Alec Irwin, and John Gershman²

In 1990, at the age of 27, Terri Schiavo suffered a cardiac arrest that would leave her in a persistent vegetative state for the rest of her life. Without any control over her body, and with questionable brain activity, Terri required round-the-clock nursing care and, what would prove to be crucial later on, a feeding tube. Her life was sustained in this way for eight years, until her husband brought the issue of discontinuing the use of her feeding tube to a Florida judge in 1998. Terri's parents, the Schindlers, immediately initiated legal opposition, and a lengthy battle in the courts ensued. For American jurisprudence and bioethics, the Schiavo case did not introduce a novel issue. It did, however, force the courts to readdress one of the more complex and emotionally-charged areas of ethics and the law.

The Florida judiciary decided that Terri's feeding tube could be removed, adhering to a legal precedent set in 1978 in New Jersey's Quinlan case and at the federal level with the case of Nancy Cruzan in 1990. The Florida legislature, impelled by conservative religious forces, moved immediately to pass a law that would put the power

¹ Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (Berkeley: University of California Press, 2003), p. 175.

² Jim Yong Kim, Joyce V. Millen, Allen Irwin, et al., *Dying for Growth: Global Inequality and the Health of the Poor* (Monroe, Maine: Common Courage Press, 2000), p. ix.

to re-insert the feeding tube into the hands of the state's governor, Jeb Bush; he quickly exercised that power. The unconstitutionality of the actions by the Florida legislature and executive was resoundingly decided by the Florida Supreme Court, and, in January of 2005, the U.S. Supreme Court let that decision stand, refusing to hear an appeal by Governor Bush. Terri's right to decline medical treatment, based on the cherished ethical principle of autonomy, was upheld, but the public battle over her life was just beginning.

Terri's parents, unwilling to see treatment end, sought to have their daughter's life maintained in a persistent vegetative state. Their deeply emotional plea was taken up by the religious right and the "culture of life,"³ powerful interest groups in the United States and in many parts of the world. Eventually, with great political and financial backing, this movement, with an abundance of U.S. mainstream media attention, brought Terri's case to a new and unlikely arena, the U.S. Congress. As George Annas, an expert on health law, bioethics, and human rights describes it: "For the first time in the history of the United States, Congress met in a special emergency session to pass legislation aimed at the medical care of one patient—Terri Schiavo. President George W. Bush encouraged the legislation and flew back to Washington, D.C., from his vacation in Crawford, Texas, so that he could be on hand to sign it immediately."⁴

The new law, "Terri's Law," violated constitutional protections of checks and balances by calling for a new ruling in a federal court, directing that the seven previous

³ The "culture of life" was introduced by Pope John Paul II in the encyclical *Evangelium Vitae* (accessed at <http://www.vatican.va/edocs/ENG0141/_INDEX.HTM> on April 5, 2007), who challenged us to choose between it and the "culture of death." In the United States, there has been a very strong faith-based following of the "culture of life," and the concept has entered into mainstream American politics around the issue of abortion.

⁴ George J. Annas, "'Culture of Life' Politics at the Bedside—The Case of Terri Schiavo," *The New England Journal of Medicine* 352 (2005), pp. 1710-1715.

years of the judicial process be ignored. Appropriately, the U.S. District Court judge ruled that the “exhaustive” legal proceedings conducted in Florida had already determined the case, and Terri’s feeding tube could legally be removed. The challenge of her parents, grasped onto and much amplified by the “culture of life,” would fail, despite plenty of media attention, popular support, and U.S. government action at the highest levels. Terri’s legal right to refuse medical treatment was restored, and she died on March 31, 2005, at the age of 41.

Olivia, a poor, unemployed Ghanaian woman in her early thirties, came to the Matthew 25 House in early March of 2006. The house is a two hour bus ride from her home in a shanty-town on the outskirts of Accra, Ghana’s capital. She went there because she knew that the Catholic NGO was one of the few places in the country where she could receive free anti-retroviral drugs to halt the full-blown AIDS that was ravaging her body; she could not afford the government subsidized rate of \$5 a month, as many of the socially and economically powerless cannot in this West African nation. Weighing only seventy pounds (one of the most dramatic indicators of her late-stage AIDS), Olivia immediately began the process that would lead to getting ARV treatment. She swallowed her shame and went in for a barrage of tests that would give doctors the information they needed to put her on the precious medications.

Though she was by far the newest and one of the weakest members of Matthew 25’s support community, Olivia was eager to become involved with the group’s outreach programs as soon as she joined. She wanted to share her story with as many Ghanaians

as she could, to ensure that the tragedy that she was experiencing would not be repeated. It was on her first outreach program that I met her. She spoke with passion and courage in a country where AIDS is highly stigmatized. She told how she came to fear that she was infected with HIV when her husband mysteriously passed away, wracked by fevers and diarrhea. With little money and her body progressively weakening, Olivia's concern for the welfare of her young son forced her past the social and cultural barriers to testing and treatment and led her to seek the help of the Matthew 25 program.

Olivia's willpower was strong on the day I heard her speak, but her physical strength was nearing an end. She could barely stand and could not walk more than a few steps. Eunice, another HIV-positive woman, carried Olivia on her back. Her story was similar to Olivia's, with one important exception: she had begun taking ARVs two years earlier and was nearly as strong as she had been before infection with HIV. Olivia was hopeful that she too would enjoy the "Lazarus effect" experienced by those with AIDS lucky enough to get treatment. Olivia, however, would not be one of the fortunate ones. A week after I met her, I spoke with Father Bobby Benson, the director of Matthew 25 House, on the phone. "How is Olivia?," I asked, "Has she got her meds yet?" The reply came slowly, "Oh...no. She was due to get them next week, but today...she died."

There is something terribly wrong with humanity today that we allow tremendous inequalities in health to define our world. Unequal attention, unequal treatment, and unequal valuing of life arise from Olivia's and Terri's stories. Their lives are at the extreme ends of the spectrum of health outcomes, but there is a monumental gap between

them where millions of injustices play out every day. This is most clear, most devastating, and most morally outraging when looking at health outcomes across the world. Such injustice calls into question the very project of human existence; what are we here for if not to care for one another, as equals? Every time we focus on the Terri Schiavos of the world to the exclusion of the exponentially greater number of Olivias, we willfully sacrifice a great portion of our humanity.

How does one address these great contradictions? Such stories indict our very capacity to be moral beings, and it is in re-claiming that morality that it is possible to search for solutions. In looking at health, bioethics quickly comes to mind as the mechanism for rectifying our moral failures. As the Schiavo case makes clear, bioethics is enjoying a great deal of prominence and influence in the societies of the developed world. But why has the discipline been so silent on issues of justice? Much of it has to do with the nature of the “first model of bioethics,” which, as a product of the Western philosophical tradition, focuses mainly on the principle of autonomy to the exclusion of justice. It has also made itself relevant to only a very small number of issues, grouped around the rapid advances in biomedicine and its technologies. Health, widely conceived, is considered outside the scope of bioethics, which limits itself to the patients who have found a place in the medical systems of the industrialized world. The millions, if not billions, who never become patients are ignored, and, thus, they are sentenced to suffer in silence. Health injustices call out for a moral response and they call bioethics to radically expand its purview.

This critique is not alone in its indictment of the first model of bioethics, and a new bioethical model is beginning to emerge as discontent with the old model nears a breaking point. Academic voices from the long-neglected developing world are joining to castigate bioethics's inattention to the plight of the poor and powerless.⁵ Those who study social inequalities have recognized that they are inevitably linked to negative health outcomes, and that bioethics must reinvent itself in order to address this relationship in a spirit of social justice.⁶ Even more promising is that bioethicists themselves have begun to reflect on the purpose of the discipline if it has nothing to say about the death and suffering that much of the world's people experience in a time when there are more resources available than ever to prevent their plight.⁷ The emerging bioethics has initiated a conversation on health, human rights, and social justice that is long past due and absolutely necessary if we hope to fully realize our collective humanity.

This analysis investigates what is wrong with the first model of bioethics by looking at the harm it causes on a global scale. The ethical debate around the worldwide ban on organ sales pits philosophers and ethicists who propose a "trade" in human organs against social scientists who have documented the suffering caused by international organ "trafficking." Market advocates rest their argument on the dominant principle of the first model of bioethics, which is autonomy; persons reign supreme over their bodies, even when it comes to selling an organ. Opponents explain that the ideal of autonomy is

⁵ Angeles Tan Alora and Josephine M. Lumitao, eds., *Beyond a Western Bioethics: Voices from the Developing World* (Washington, D.C.: Georgetown University Press, 2001).

⁶ Renee C. Fox and Judith P. Swazy, "Examining American Bioethics: Its Problems and Prospects," *Cambridge Quarterly of Healthcare Ethics* 14 (2005), pp. 361-373.

⁷ Larry R. Churchill, "Are We Professionals? A Critical Look at the Social Role of Bioethicists," *Daedalus* 128 (1999), pp. 253-274.

merely illusory, and that the social and economic realities of organ vendors make the decision to sell an organ not an individual “choice,” but actually exploitation.

The failure of bioethics, in the organ case, is not simply a lack of attention to injustice; the crime is that its theory serves to perpetuate injustice on the vulnerable. This harm is caused by the discipline’s myopic vision. It focuses on Eurocentric individual rights without taking into account the larger social sphere that inhibits the agency of the powerless. Thus, many consider such a narrowly-conceived bioethics to have lost its grasp on what is truly moral. Bioethics tells us nothing about our responsibilities to others, but only about individual rights in the exclusive world of biotechnology.⁸ The new model is an attempt, then, “to bring the moral, conceived as a dimension of all relationships forged in the context of the lived world of local communities, in conversation with bioethics, seen as the application of a set of codified norms to the practice of medicine.”⁹ If bioethicists reflexively interrogate their own discipline, they will be able to reclaim its moral weight in action, rather than manage inequality through ignorance.

The second section of the paper looks at how bioethics is reinventing itself, and it looks at the national case of South Africa to see how this proposal for a new bioethics is gaining currency. The new model of bioethics is based on using the language of human rights and social justice to discuss health in any context. It is founded upon an understanding of the social determinants of health, along with the great challenges that

⁸ Laurie Zoloth, “Heroic Measures: Just Bioethics in an Unjust World,” *Hastings Center Report* 31 (2001), pp. 34-40.

⁹ Veena Das, “Public Good, Ethics, and Everyday Life: Beyond the Boundaries of Bioethics,” *Daedalus* 128 (1999), p. 99.

the HIV/AIDS pandemic holds for all of human society. With a new language of analysis, this new bioethics can explore the social history of a place as medicine would a patient, and it can prescribe appropriate remedial actions.

South Africa has one of the simplest social diagnoses but the gravest health challenges of any of the world's nations. The tremendous injustices of South Africa's history, manifested in the evils of apartheid, have shaped to a large degree who is healthy and who is sick in the country today. South Africa's HIV/AIDS pandemic shows in no unclear terms the way in which disease is determined by a place and a patient's past and the threat it poses to their future. The application of the new bioethics in the present holds great promise for overturning the cycle of suffering.

The third case, then, shows the achievement of the Treatment Action Campaign (TAC) in putting this proposed bioethics into political action by campaigning for access to antiretroviral treatment (ARVs) in South Africa. TAC's local activism has had national, regional, and global influence by passionately striving for the realization of health care as a human right for those infected with HIV. Using the civil and political rights ensured by the democratic triumph over apartheid, TAC has engaged the court system to challenge the lack of political will to fight AIDS as a violation of social and economic rights. Though TAC's victory revolved around a single issue, access to ARVs, their achievement opens discussion of the right to a broader provision of social and economic rights. It also raises the major issue of implementation, guided by the ideal of universal and equitable health care. Is there an "ethics of implementation," and how must we balance the radical ideal of health as a human right with the more pragmatic and

immediate goal of providing services to some right away? It is possible to answer these questions with the new model of bioethics that stresses action and obligations to others over individual rights. Global health equity requires, then, a more complete shift in the bioethical agenda and a total re-structuring of our moral priorities in health. The language of human rights and social justice provide the essential framework for holding this discussion.

1. The Problem: Organ Sales and the Harm of Bioethics

Pointing out the insufficiencies of a principle-based approach to bioethics is certainly not a novel academic critique.¹ An important new step, however, is to build on those critiques to show that such a model is not just theoretically inadequate, but unambiguously *harmful* as it touches the lives of those whose daily reality is anything but autonomous. The harm caused by the first model of bioethics is most pernicious in the debate around an “ethical” market in human organs.

Organ sales proponents rely exclusively on the first model of bioethics to carve out a legitimate sphere for a discussion of a “trade” in human organs. Thus, the cornerstone of their argument is the dominant bioethical principle of autonomy. Their argument is particularly insidious precisely because it is so convincing from the perspective of the “liberal” Western tradition. Interrogating the roots of that tradition, however, lays bare the ultimate harm caused by overdependence on the value that we in the West consider to be the bedrock of a “free” society.

A discourse of resistance to organ sales emerged first from medical anthropologists in the developing world, whose work among the poor and powerless gave them the necessary vantage to recognize the harmful effects that organ commodification had on the health of the socio-economically exploited. A sizeable literature has chronicled the negative health outcomes that sales of organs have had on the powerless

¹ Barry Hoffmaster, ed., *Bioethics in Social Context* (Philadelphia: Temple University Press, 2001); Dan W. Brock, “Broadening the Bioethics Agenda,” *Kennedy Institute of Ethics Journal* 10 (2000), pp. 21-38; Leigh Turner, “Bioethics, Social Class, and the Sociological Imagination,” *Cambridge Quarterly of Healthcare Ethics* 14 (2005), pp. 374-378.

across the developing world. It is necessary to expose these harmful effects as direct results of misplaced faith in the first model of bioethics and the principle of autonomy.

“Life for Life”?

The argument against banning organ sales arose in the same way that many challenges to traditionally-held values do: as a desperate appeal in a situation of great moral urgency. The urgent moral crisis was and is the great gap between the number of patients waiting for an organ transplant and the number of transplantable organs that are actually available. The Organ Procurement and Transplantation Network presently has 95,323 candidates on its waiting list, representing the total number of transplant candidates in the United States; 70,870 of these candidates are waiting for a kidney transplant. Only 28,931 transplants were performed in 2006, while 6,038 people died while waiting for a transplant.^{2,3} It is the moral urgency of saving thousands of lives with increased transplants that drives the proponents of a market in human organs, a market that it is believed will erase the “lethal gap” between supply and demand.⁴

Such a solution, however, is currently illegal in the United States, Europe, and much of the rest of the world. The World Medical Association and the World Health Organization have also made statements against organ sales. The nearly ubiquitous worldwide ban on a market in organs came about in the 1980s, as advances in medical technology made transplantation the best treatment option (as opposed to dialysis, in the

² As of March 30, 2007. Accessed at <<http://www.optn.org/latestData/rptData.asp>>.

³ A. Ojo, J. Hanson, H. Meier-Kreische, et al., “Survival in recipients of marginal cadaveric donor kidneys compared with other recipients and wait-listed transplant patients,” *Journal of the American Society of Nephrology* 12 (2001), pp. 589-97.

⁴ Arthur Caplan, “Transplantation at Any Price,” *American Journal of Transplantation* 4 (2004), pp. 1933-1934. “Lethal gap” is Caplan’s term, but he is actually an opponent of organ sales.

case of renal disease). The rationale behind such a ban was less a thoughtful discussion of ethics and values than it was an immediate and emotional response of moral repugnance to the idea of selling an organ. The ban rested on the presumed moral high ground that organ sales were a basic violation of human dignity. With transplantation still a novel procedure and relative benefits versus other treatments still in doubt (transplantation was considered best, but not by much), any questioning of the moral assumption of the ban on sales remained outside of the ethical arena.⁵

Twenty years later, however, a sizeable minority of ethicists and philosophers have brought the possibility of a market in organs into mainstream bioethical discussion. At present, transplantation is, incontrovertibly, the best treatment option for many conditions, especially end-stage renal disease. Improvements in immunosuppressive capabilities and infection prophylaxis have led to survival rates that are better than those for dialysis as well as less traumatic for the patient.⁶ Financial compensation for living donors has come to be seen as a realistic option for solving the organ shortage, especially as survival rates for recipients of transplanted organs from living donors have outpaced those for organs obtained from cadavers.⁷ One year after the transplant, there is a 97.9% survival rate for patients who obtained kidneys from living donors compared to an 94.5% survival rate when the kidney was obtained from a cadaver. After five years, the trend is more striking, with kidneys from living donors correlating to a 90.2% survival rate as

⁵ Arthur J. Matas, "The Case for Living Kidney Sales: Rationale, Objections, and Concerns," in *The American Journal of Transplantation*, 2004 (4), pp. 2007-2017.

⁶ R.A. Wolfe, V.B. Ashby, E.L. Milford, et al., "Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant," *New England Journal of Medicine* 341 (1999), pp. 1725-1730.

⁷ P.I. Terasaki, M. Cecka, D.W. Gjerston, et al., "High survival rates of kidney transplants from spousal and living unrelated donors," *New England Journal of Medicine* 333 (1995), pp. 333-336.

opposed to 82.0% for kidneys from cadavers.⁸ It is thought that a market in organs from living donors would reduce the lethal gap and would encourage the best possible organs into the donor pool.

From a recognition of an urgent moral crisis on the demand side of the equation, those who propose a market solution move to address where saleable organs would come from. It is not the economically secure, to be sure, who are most likely to part with a “spare” kidney. Putting their faith in the “free market,” proponents insist that organ sales would be beneficial both for those who receive organs and those who provide them. Transplant recipients would get the optimal life-saving treatment, while the organ sellers would receive a considerable monetary sum⁹ that would greatly improve their economic situation. That the poor alone would be organ vendors is irrelevant, it is believed, and organ sales are considered a good option for alleviating poverty. That the simple exchange of organ for money is enriching for all parties involved is the basic assumption of the “life for life” argument, and it is an attempt to achieve an unassailable moral high ground for a proposal that has long been contentious.

Market advocates acknowledge an initial moral repugnance to the idea: “No doubt, discussing payment can be unpleasant; it would be ideal if we could increase the supply of kidneys without resorting to payment. However, after four decades of trying to increase the number of kidneys, we still are left with an ever-increasing organ

⁸ As of March 30, 2007. Accessed at <<http://www.optn.org/latestData/rptStrat.asp>>. The comparison holds true for transplanted livers and lungs as well, though the difference in survival rates is less striking and can actually prove worse in the case of lung transplants three and five years after the transplant.

⁹ In one study, a “cost-effective” fixed price on purchased kidneys was pegged as high as \$225,000. Arthur J. Matas and Mark Schnitzler, “Payment for living donor (vendor) kidneys: A cost-effectiveness analysis,” *American Journal of Transplantation* 4 (2003), pp. 216-221.

shortage.”¹⁰ Janet Radcliffe-Richards, a British philosopher prominent in the market solution school of thought, challenges that the ban on sales and all arguments against a market are in fact reactionary from a moral standpoint: “But what is the moral basis of this opposition? If you think organ selling should remain illegal, what exactly is your reason? Is it that you regard selling body parts as wrong in itself, irrespective of consequences? Or is it because you think that although it is not wrong in itself, in practice the harms will usually or always outweigh the benefits?”¹¹

Radcliffe-Richards and others caution that though the discussion of organ sales is morally unpalatable at first glance, the greater moral outrage, in a deeper analysis, is that thousands are dying on waiting lists while a potential solution is banned. The burden of proof, advocates of organ sales feel, should lie with those who wish to maintain these harmful prohibitions. The invitation is to a debate of ethical principles; proponents place their full trust in the dominant principle of bioethics, autonomy, and they challenge those favoring the ban to explain why autonomy does not include the right to sell an organ.

The Centrality of Autonomy

Over himself, over his own body and mind, the individual is sovereign. . . . The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.

John Stuart Mill¹²

Reverence for the rights of the individual have a long history in the Western tradition. The notion of natural rights has occupied prominent thinkers since the Age of Revolution in the eighteenth century. Any discussion of rights in the West is based on the

¹⁰ Matas (2004), p. 2008.

¹¹ J. Radcliffe-Richards, “Commentary: An ethical market in human organs,” *Journal of Medical Ethics* 29 (2003), p. 140.

¹² John Stuart Mill, *On Liberty* (New York: Bartleby, 1999).

assumption that the unit of such a discussion is the individual. The freedom of the individual to self-determination, be it philosophical or legal, is the gold standard of any Western rights-based approach. Civil and political rights maintain their hegemony vis-à-vis social and economic ones. Bioethics, an offshoot of Western philosophy and ethics, has overwhelmingly focused on protecting and promoting autonomy. It underpins all manner of cases, including the right to die, the right to refuse treatment, and the right to informed consent. The principle of autonomy is the linchpin of the organ sales debate, and the harm it causes is directly related to its preeminence in Western thought.

Infringing upon one's autonomy, Isaiah Berlin argues in his famous discussion of liberal values, is the worst offence one can commit against another's humanity.¹³ One's individual sovereignty is the very essence of what makes her or him human, according to the earliest conceptions of civil rights. Autonomy as freedom has led to a tendency to believe that individual choice is all that society is obligated to ensure. Once a person is free to choose, responsibility for the outcome remains in the decision-maker's hands. Social obligations have little place in such an epistemology.

In 1979, Tom Beauchamp and James Childress laid out four principles that would indelibly shape the emerging field of bioethics when they published their now classic textbook, *Principles of Biomedical Ethics*: 1) the principle of nonmaleficence, the Hippocratic duty to do no harm; 2) the principle of autonomy; 3) the principle of beneficence, the duty to do good; and 4) the principle of justice.¹⁴ The approach of these

¹³ Isaiah Berlin, *Four Essays on Liberty* (Oxford: Oxford University Press, 1969), pp. 136-137.

¹⁴ The most recent edition is Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*, 5th ed. (Oxford: Oxford University Press, 2001).

Georgetown University ethicists would come to be known as the “Georgetown Mantra” and it defined the field of bioethics for the next two decades. The four principles were meant to provide a middle ground between moral theory and ethical practice so that physicians would have a guide in their relationships with their patients. The principles also provided a common language for bioethicists to discuss the moral dilemmas arising from the introduction of new medical technologies. One principle came to dominate ethical discussion: autonomy was the only contentious area left, after physicians remembered to do no harm, to do good, and to treat their patients equally.

Autonomy is principally concerned with ensuring that patients’ rights are not violated as they are the most vulnerable party in the healthcare system. In one often-cited example, it protects the rights of Jehovah’s Witnesses to refuse life-saving blood transfusions against the wishes of all other parties, most notably the doctors giving them treatment. It creates a generally applicable rule to protect patients from the dangers of medical paternalism and to have ultimate control over their own bodies and whatever treatment is provided to them.

A corollary of the principle of autonomy is informed consent. It has ensured that all patients and potential patients understand and positively agree to undergo any medical procedure. Since *Slater v. Baker and Stapleton* in 1767, patients have been afforded the right to knowledgeably make important medical decisions. Informed consent is primarily focused on the ideal physician-patient relationship, where communication and understanding flow freely between both parties and the patient’s decision is uncolored by any form of coercion.

Autonomy and informed consent are given by advocates of organ sales as the justifications for one to be able to sell an organ. They argue that a ban on organ sales is unjustly depriving those who would choose to sell an organ of the right to make autonomous decisions regarding their own bodies. In all manner of cases, it is argued, individuals have the right to put their bodies in harm's way in exchange for money that can be used to obtain that which they value. One author gives the example of firefighters and deep-sea divers, who accept an increased risk of death and injury in exchange for increased salary.¹⁵ If we allow individuals to subject themselves to potentially harmful outcomes in other cases, why would we not allow organ vendors to do the same?

This reasoning is coupled with the knowledge that the present system of donation by definition makes an organ a commodity that an individual can part with. If one can donate a non-essential organ, then the only difference between donation and sale is an economic one. Organ sales should be allowed "prima facie," then, because the law already permits legal donation and because sales of other parts of human bodies are allowed, such as blood, sperm, and eggs. The "motive of monetary self-interest," they argue, is not in itself illegal. Therefore, the sale of an organ could not be illegal.¹⁶

The argument then turns to the perceived situation of the organ vendors, whose autonomy is in question. In many cases, potential organ vendors are "anxious to sell." Denying them this right to sell is harmful to them, just as it is harmful to those who die on the waiting list without receiving these available organs. It is Western paternalism to

¹⁵ J. Savulescu, "Is the sale of body parts wrong?," *Journal of Medical Ethics* 29 (2003), pp. 138-139.

¹⁶ M.B. Gill, R.M. Sade, "Paying for kidneys: the case against prohibition," *Kennedy Institute for Ethics Journal* 12 (2002), pp. 17-45.

maintain that the poor, who are usually as desperate to sell a kidney as someone on the waiting list is to receive one, be deprived of one choice to improve their economic situation.¹⁷ Limiting the available options, as a prohibition on sales does, infringes upon autonomy while making it harder for the poor to “develop.”

Organ sales advocates fear that much of the debate ignores the reality that an unregulated market already exists. This illegal and decidedly global black market often has a negative effect on donors, who are underpaid, exploited, and very poorly cared for after the primary transaction occurs. Not only does the existence of this market provide proof of the economic desire for organ sales, but some believe that the creation of a legal market would be able to solve the problems that characterize the black market. The legal market would be supported by regulatory institutions that would ensure that organ sales benefited both parties. Market proponents suggest “a central purchasing system, to provide screening, counselling, reliable payment, insurance, and financial advice.”¹⁸

Within the school that supports a market solution, there is a fair amount of debate over what an ethical market would look like. Such a discussion recently took place in the pages of the *Journal of Medical Ethics* among ethicists and philosophers from UK. Charles Erin and John Harris co-authored an article that outlined the “bare bones” of an ethical market in human organs: “the market would be confined to a self governing geopolitical area such as a nation state or indeed the European Union... There would be only one purchaser, an agency like the National Health Service (NHS), which would buy

¹⁷ J. Radcliffe-Richards, A.S. Daar, R.D. Guttman, et al., “The case for allowing kidney sales,” *Lancet* 352 (1998), pp. 1950-1952.

¹⁸ *Ibid.*, p. 1951.

all organs and distribute according to some fair conception of medical priority.”¹⁹ Any regulation of a market is meant to protect the well-being of organ vendors while still enticing a sufficient number of organs into the health system. Radcliffe-Richards counters with a more extreme vision:

Of course there is something undesirable about a one way international traffic from poor to rich; but that is not enough to settle the all-things-considered question of whether it should be allowed. Much international trade is currently objectionable on the same grounds, but simply stopping it would be worse for the poor countries. It is much better, for them, to improve the conditions of trade than to prevent it altogether. Is the case different with organs?²⁰

Her argument makes clear that, at root, an argument for organ sales is founded on the basic ideology that individuals are completely autonomous over themselves and the free market is the means to progress.

Against Harmful Sales

In general, the circulation of kidneys follows established routes of capital from South to North, from East to West, from poorer to more affluent bodies, from black and brown bodies to white ones, and from female to male or from poor, low status men to more affluent men.

Nancy Scheper-Hughes²¹

Opposition to organ sales is driven by a perspective that focuses on the social determinants of health and illness with a truly global lens. They explore the political, economic, cultural, and historical context that must be applied to the organ trade phenomenon. Critical medical anthropologists and investigative journalists were the force behind this initial push, with a limited number of ethicists now joining the fray. At root, opponents of organ sales share common ground with those who advocate for a market

¹⁹ Charles A. Erin and John Harris, “An ethical market in human organs,” *Journal of Medical Ethics* 29 (2003), pp. 137-138.

²⁰ Janet Radcliffe-Richards (2003), p. 140.

²¹ Nancy Scheper-Hughes, “Keeping an eye on the global traffic in human organs,” *Lancet* 361 (2003), pp. 1645-48.

solution. They too are disturbed by the lethal gap between the demand and supply of organs, and they recognize the inability of the altruistic donation system to close it. They believe, however, that a market in organs is not an appropriate solution to the organ shortage. Based on their observations of the unregulated black market, these opponents of organ sales are unwilling to accept the moral and social consequences of a regulated system that pays for kidneys and slices of parts of healthy livers. Those who oppose organ sales examine the forces that provoke desperate vendors to sell their body parts, and they attempt to determine the implications for global society. They too identify a moral crisis, but it is for the exploited organ sellers that they voice this concern. Bioethics's ignorance of the social context of the organ debate allows it to be used to perpetuate inequality rather than resolve it.

In following those on the political-economic margins, the Organs Watch team at the University of California, Berkeley has provided the clearest picture of the unregulated black market traffic in human organs. They have concluded that far from being an autonomous choice on the model of John Stuart Mill or Isaiah Berlin, the decision to sell a kidney or other organ is one that is forced on society's most vulnerable through socio-economic forces and the demand created by the organ shortage in developed countries. Instead of a positive, "life for life" choice that raises organ sellers up out of their conditions of poverty and marginalization, Nancy Scheper-Hughes (a leading medical anthropologist) and others have found that the decision to sell an organ is in fact a non-choice produced by those conditions; it almost always marginalizes organ sellers further. The primacy of the greater social context is underscored by an article on Iraq that

appeared as that country began to plummet into chaos: “Black market organ trade is Iraq’s new growth industry.”²² Rather than drive taxis or become policemen for fear of suicide bombers and death squads, young Iraqi men have found that their best option is to have their kidneys removed and sold in dingy Baghdad hospitals for as little as \$700. This choice is directly linked to the increasing instability of their society.

Arthur Caplan, an American bioethicist who worked towards a ban on organ sales in the United States in the 1980s, also refutes the premise that an organ market would be founded on a respect for autonomy: “On ethical grounds, . . . the issue is not the rational capacity of the seller, but the likely absence of real alternatives.”²³ There are other situations in which the poor must resort to extreme means out of desperation for money. We do not hold these choices up as models of rational choice. Caplan provides the example of those who resort to selling their children to survive; certainly it is not okay just because it relieves some of the immediate poverty of the oppressed. The decision to sell an organ is not much different. The New York Times journalist Larry Rohter gives us a poor Brazilian’s appraisal of his options: “In order not to have to steal or kill, I thought it best to sell my kidney.”²⁴ Structural violence forces these terrible decisions on the poor, and it makes them vulnerable to the attendant suffering of a kidney donation in the developing world.

Much of the Indian experience with organ sales (which were legal there until 1994), was unearthed by Lawrence Cohen in his work there as a medical anthropologist

²² Saleh Al Jibouri and Colin Freeman, “Black market organ trade is Iraq’s new growth industry,” *Sunday Telegraph* (22 May 2005), p. 24.

²³ Caplan (2004), p. 1933.

²⁴ Larry Rohter, “Tracking the sale of a kidney on a path of poverty and hope,” *New York Times* (23 May 2004), p. A1.

for Organs Watch.²⁵ His interviews with Indian women who sold their kidneys in Chennai reveal, at first glance, an element of choice: “Yes, I would do it again if I had another to give.” Their addendum, however, captures their diminished agency: “I would have to.” Scheper-Hughes explains why the bioethical model fails with regard to organ sales, since it lacks the appropriate social context: “Bioethical arguments about the right to buy or sell an organ or other body part are based on Euro-American notions of contract and individual choice. *But these create a semblance of ethical choice in an intrinsically unethical context.*”²⁶ Autonomy can be applied in ideal circumstances, but it is harmful rather than helpful in the context of exploitation and oppression that defines vulnerable lives.

The arguments for an organ trade theorize that monetary incentives would prove nothing but beneficial to organ vendors. Those who compile ethnographies of the experiences of actual organ vendors, however, find a much different reality. Ethical arguments for sales focus on the primary transaction of organ for money, while extensive follow-up interviews catalogue the devastating secondary phenomena that often accompany the sale of an organ. Cohen explains that, “the problem with an ethical argument of this sort is the unrelenting presumption that ethics can be reduced to a primary transaction.”²⁷ His research shows that social and economic forces both determine the “choice” to sell for Indians in “kidney belts” and where the money will go afterwards. Moneylenders in these areas push more aggressively for debts to be paid,

²⁵ Lawrence Cohen, “Where it Hurts: Indian Material for an Ethics of Organ Transplantation,” *Daedalus* 128 (1999), pp. 135-165.

²⁶ Scheper-Hughes (2003), p. 1646. Emphasis mine.

²⁷ Cohen (1999), p. 148.

knowing that the extremely poor have at least one available asset, an extra kidney. One half of the “life for life” equation is upheld, in that the kidney takes a straight path from the poor seller to the affluent buyer, but the money meant to pull the seller out of poverty is diverted into the hands of brokers and debt collectors.

South Africa’s *Sunday Times* tells the story of Alberty da Silva’s money, after the poor Brazilian sold his kidney to a middle-aged woman in Brooklyn:

Then, Da Silva’s cash evaporated. His two former girlfriends, the mothers of his children, made off with a large chunk of it and, with what remained, Da Silva bought a used car to look for work. When he couldn’t meet the monthly payments, he downgraded to an old jalopy. When the jalopy broke down almost immediately, he traded it for a second-hand bicycle. The bicycle and a pair of running shoes are all he has left to show for the sale of his kidney—that, and a huge, disfiguring, sabre-like scar across his midsection.²⁸

In economic terms, Da Silva is just barely better off having sold his kidney. But a bioethical analysis leaves out another important aspect. Embodied social suffering must be taken into account to give a full picture of the individual consequences of selling one’s kidney. The immediate suffering of the surgery itself is also raised by this case. Both Da Silva and the Brooklyn buyer were flown into South Africa to illegally undergo the operation. She was put up in a five-star hotel before and for a week after the surgery. He, on the other hand, was put in a dingy apartment and quickly flown back to Brazil. The inequities in treatment before and after the surgery put into question the procedure itself. One can only speculate, but it would not be unreasonable to assume that the surgeons might be a bit less painstaking with the powerless Brazilian vendor.

The suffering of those who sell their organs is not only physical, but also emotional. In Moldova, young kidney sellers demonstrate one distressing example of

²⁸ Suthentira Govender and Jocelyn Maker, “Selling his only ‘spare’ asset,” *Sunday Times* (21 August 2005), p. 8.

social ostracism and stigmatization, but one that is far from unique. One man in his late twenties said: “They call us prostitutes. . . . Actually, we are worse than prostitutes because we have sold something we can never get back. We are a disgrace to our families and to our country.”²⁹ Moldovan kidney sellers suffer consequences with their families, their work, their religion, and even potential marriages. In addition to social pain, they, like many kidney sellers in the developing world, are unable to access medical care for any post-operative complications. They often receive inferior care throughout the whole transplantation process, and, in some instances, they will even be refused follow-up care at the very hospitals that took their kidney and gave it to someone else.

The ultimate fallacy of the “life for life” argument is evident from a recent Indian study of 305 individuals who sold kidneys in Chennai. The results proved that organ vendors were worse off both economically and health-wise, hardly the ideal situation proposed by Western ethicists and philosophers:

Ninety-six percent of participants sold their kidneys to pay off debts. The average amount received was \$1070. Most of the money received was spent on debts, food, and clothing. Average family income declined by one third after nephrectomy, and the number of participants living below the poverty line increased. Three fourths of participants were still in debt at the time of the survey. About 86% of participants reported a deterioration in their health status after nephrectomy. Seventy-nine percent would not recommend that others sell a kidney.³⁰

Undoubtedly, the evidence obtained from social scientists disproves the claim that organ vendors would benefit economically from organ sales without any deterioration in their health. Instead, organ sales ensure that the poor are further exploited and that they are actually worse off as the wealthy benefit from their suffering.

²⁹ Scheper-Hughes (2003), p. 1647.

³⁰ Madhav Goyal et al., “Economic and Health Consequences of Selling a Kidney in India,” *Journal of the American Medical Association* 288 (2002), pp. 1589-1593.

It is undeniable that organs have become a precious commodity for those who need a transplant and for those who are desperate enough for money to sell one. In many parts of the developing world, “the kidney as a commodity has emerged as the gold standard in the new body trade, representing the poor person’s ultimate collateral against hunger, debt, and penury.”³¹ Social scientists remind us that the organ trade phenomenon can be subject to an ethical discussion only if the social context that it is embedded in is truly considered.

The Failure of Bioethics

Why, then, does bioethics permit such a debate to rage on and even gain in prominence as the shortage in transplantable organs grows? The South African bioethicist Solomon Benatar gives some answers by critiquing the “inadequate and narrow” framework of his own discipline:

First, the focus on saving lives is myopic, with the lives of the most privileged in the world receiving most attention. Secondly, the debate is firmly set within a value system in which market values dominate. Thirdly, health is considered from a highly individualistic perspective with little understanding of the importance of social solidarity in health. Finally, a constricted moral vocabulary is used to discuss the ethics of organ sales.³²

Recognizing its own shortcomings is a harsh and difficult task for bioethics, but a healthy reflexivity will ultimately make the discipline stronger. Benatar and others don’t suggest discarding bioethics as irrelevant to health and morality. Rather, they propose that bioethics reshape its priorities and expand its vision. The organ sales debate is a disheartening and harmful failure. But the most important lesson to be gleaned is that bioethics must seek new ways of looking at health across the globe. Recent developments

³¹ Scheper-Hughes (2003), p. 1645.

³² Solomon R. Benatar, “Blinkered bioethics,” *Journal of Medical Ethics* 30 (2004), pp. 291-292.

in the field show that bioethics is beginning to do just that. In reinventing itself, bioethics is gaining the potential to benefit vulnerable populations instead of exploiting them.

2. The Proposal: Bioethics, Health, and Human Rights

Recognizing the harm and failure of the first model of bioethics is but a diagnosis. The obligation, then, is to find an ethical remedy that can address the plight of exploited organ vendors and make the health of the socially invisible, like Olivia, a moral priority. In the past decade, a comprehensive proposal for a new bioethics has begun to surface. This new model coalesced around three main insights. The first is a development that built on the long-standing recognition in public health, that health outcomes are very often socially determined. The added insight was that this did not simply provide a way to analyze public health, but that it proved that inequalities in health throughout the world are largely a product of systematic injustices; any solution would have to address the social roots of inequality.¹ The second insight was the “exceptional” nature of the HIV/AIDS pandemic. The challenges that it poses call for a much more effective way of analyzing and improving global health, and the failure to adequately respond has been a moral failure of the highest order. The final insight, and the one that would give the new model of bioethics its language and theoretical framework, came from Jonathan Mann whose work as a public health official battling the HIV/AIDS pandemic gave him the broad perspective necessary to tie the developments in global health together. He proposed that the language of human rights must become central to public health and ethics in order to move towards health equity in the global arena and responding in the best way to the juggernaut of HIV/AIDS.²

¹ Giovanni Berlinguer, “Bioethics, health, and inequality,” *Lancet* 364 (2004), pp. 1086-1091.

² Jonathan M. Mann, “Medicine and public health, ethics and human rights,” *Hastings Center Report* 27 (1997), pp. 6-14.

The result is an emerging discourse in bioethics that is able to discuss health as a human right, universally. This analysis will outline the development of this new bioethics and apply it on a national scale to South Africa, a country where social history and present realities invariably shape health outcomes, where the HIV/AIDS pandemic influences all things, and where a human rights analysis of health is desperately needed.

The Social Determinants of Health

Modern medicine generally does an excellent job of telling us *how* people become sick: AIDS is caused by a microscopic virus that weakens our immune systems, ultimately making us vulnerable to and unable to fight off other illnesses; high cholesterol is partly a result of the information coded in our DNA and partly a result of the foods we eat; cancer is the abnormal growth of our bodies' own cells, which can be a product of bad habits (like smoking), carcinogens in our environment (like radiation), or mechanisms science doesn't yet understand. What medicine can't tell us is *why* many people become sick because this is dependent on myriad forces that shape the reality of everyday life.

Broadening our analytical perspective to include social realities gives us a much different picture of the preceding medical conditions. The foods that are high in fat and cholesterol are often the cheapest ones in the supermarket or fast-food restaurants, and thus they are the most cost-effective option for the poor in wealthy countries, like the United States; consequently they are purchased, ironically, on the grounds that they provide the best means of survival. In turn, the low prices of highly processed foods are heavily dependent on the political history of the U.S. farm bill that subsidizes farmers to

overproduce crops like corn and soy from which those foods are derived.³ Cancer caused by the environmental damage done by industry, like contaminated water or air pollution, overwhelmingly effects the poor, whose low incomes put them in the cheap housing near industrial centers and whose lack of political voice prevents their complaints from being heard.⁴ AIDS transmission is determined by much more than the HI virus's ability to penetrate the body's defenses: a girl sold into prostitution in an Indian slum by her desperate parents, will not simply attribute her HIV positive status to a sexual act, but will also point to the economic forces that drove her parents' farm into ruin and the cultural stigma of her gender that made her an expendable person.^{5,6} Health is much more than the biological processes that effect individual bodies; it includes the social environment in which we live, national political history, and many other aspects of human interaction.

The ways in which we experience illness and good health, strength and suffering, are bound up in the social forces that mold human life. The complexities of social, cultural, economic, and political interactions on local, national, and global scales must be the framework used to analyze health outcomes. This is by no means a simple task. It requires facility with a great many disciplines as well as the humility to realize that no single discipline has a monopoly on the right answers. Two that have been especially

³ Michael Pollan, "You are what you grow," *New York Times Magazine* (22 April 2007), p. 15.

⁴ Tanja Pless-Mulloli, Peter Phillimore, Suzanne Moffatt, et al., "Lung Cancer, Proximity to Industry, and Poverty in Northeast England," *Environmental Health Perspectives* 106 (1998), pp. 189-196.

⁵ The *New York Times*' Nicholas Kristof has brought a great deal of attention to the "slavery" that fuels prostitution in India and other parts of the world. An exemplary article is: "The 21st-Century Slave Trade," *New York Times* (22 April 2007), p. A13.

⁶ Amartya Sen has chronicled the millions of "missing women" in the populations of Asia and Africa because of the social and cultural practices of sex selection. "Missing women," *British Medical Journal* 304 (1992), pp. 587-588.

adept at exploring the social determinants of health are public health and medical anthropology. Since the early 19th century, public health has recognized the basic relationship between social conditions and health, and much more recently, social epidemiology emerged as a way to study how social position structures risk for disease.⁷ The relatively young discipline of medical anthropology has also shed light on the many forces that determine health outcomes. Its ambitious agenda relies on ethnographies of vulnerable individuals to investigate “the destructive signature of poverty and oppression on the individual and social bodies.”⁸ Inquiry ranges from the medical significance of unique cultural modes of thought to the political and economic histories of nations and particular communities.

As leaders in the movement to see health in a social context, public health and medical anthropology have important theoretical lessons for a bioethics that wishes to be truly relevant to the complexities of human health. More importantly, perhaps, is the passion for justice and health equity that guides many public health strategies and the academic activism of medical anthropology. Analytical accuracy is a first step, but finding solutions to the negative health outcomes created by social inequality is essential. “Socializing” bioethics is a precondition for ultimately working towards justice in health.⁹

⁷ Nancy E. Kass, “Public Health Ethics: From foundations and frameworks to justice and global public health,” *Journal of Law, Medicine & Ethics* 32 (2004), p. 235.

⁸ Nancy Scheper-Hughes, *Death Without Weeping: The violence of everyday life in Brazil* (Berkeley: University of California Press, 1992), p. 533

⁹ Paul Farmer and Nicole Gastineau Campos, “New Malaise: Bioethics and Human Rights in the Global Era,” *Journal of Law, Medicine & Ethics* 32 (2004), pp. 243-251.

At the center of a socially contextualized analysis of health is economics. Poverty is the root of suffering in an increasingly interconnected world: “Poverty wields its destructive influence at every stage of human life, from the moment of conception to the grave. It conspires with the most deadly and painful diseases to bring a wretched existence to all those who suffer from it.”¹⁰ The dynamic between poverty and illness is a discouraging and damaging cycle: poverty causes illness and illness causes poverty.¹¹ This deadly synergy applies to the poor individuals that it entraps just as easily as it applies to entire nations that diseases like HIV/AIDS can economically cripple.

The inequality of the global economic system that we operate in today and that fuels the deadly dynamic between poverty and illness is widely recognized outside of the United States to be characterized by dependency of the poorer countries on the wealthier ones. Ideologically, the world’s most powerful and wealthy country refuses to acknowledge the harm that its “progress” has caused. One of the founders of the dependency theory, the Brazilian economist Theotonio Dos Santos, explains its main points: In the colonial and financial-industrial periods, the economies of Latin American and other of today’s developing countries were ravaged by the exportation of precious natural resources, material and human. This created enormous profit for the developed countries of the world, elsewhere described as the “core”. In turn, allowing the core countries to further entrench their dominance vis-à-vis the “periphery”, made up of many

¹⁰ World Health Organization, *Bridging the Gaps* (Geneva: World Health Organization, 1995), p. 5. Cited in Farmer (2004), p. 50.

¹¹ Jon Fuller and James F. Keenan, “Educating in a Time of HIV/AIDS: Learning from the Legacies of Human Rights, the Common Good, and the Works of Mercy,” Julian Filochowski and Peter Stanford, eds., *Opening Up: Speaking Out in the Church* (London: Darton Longman & Todd, 2005). Fuller and Keenan attribute the poverty causes illness connection to Paul Farmer’s work and the illness causes poverty relationship to the work of Jeffrey Sachs.

of the countries that we consider underdeveloped today, resulted in a process of growing inequality.¹² It is this global inequality that allows the powerful to be healthy, on the whole, and this privileged position is directly connected to the suffering experienced by the poor and powerless.

Jim Kim and his colleagues at the Institute for Health and Social Justice have compiled one of the largest volumes detailing how global health is negatively influenced by neo-liberal economic policies and the resulting global inequality. The title, *Dying for Growth*, leaves no mystery as to the effects of an economic system that puts progress ahead of human rights. From sub-Saharan Africa, to Latin America, to post-Soviet Russia, the authors outline the deleterious outcomes that result from systematic poverty, crushing individual and public debt, and national economic restructuring in the aftermath of Communism's fall.¹³ The direct causal link between poverty and illness finds its substance in the myriad studies of health among the poor. The link also calls into question all of the notions of progress and development that come out of the developed world. How should we gauge successful societies, when economic growth and inequalities are causing death and suffering? Economists like Jeffrey Sachs and Amartya Sen, explore the other side of the coin, but reach a similar conclusion about the inadequacy of their own discipline to gauge human progress.

Denial of social and economic rights, like the rights to education, housing, and healthcare, to the people of the developing world and the marginalized populations here

¹² Theotonio Dos Santos, "The Structure of Dependence," Mitchell A. Seligson and John T. Passe-Smith, eds., *Development and Underdevelopment: The Political Economy of Global Inequality*, 3rd ed. (Boulder: Lynne Rienner Publishers, 2003), pp. 279-280.

¹³ Kim, Millen, Irwin, et al., (2000).

in the developed world, are essentially “unfreedoms” that entrench the place at the bottom of society for the most vulnerable.¹⁴ This is the illness causes poverty link; as long as social systems are designed in such a way that some have access to healthcare and others do not, those who are denied their human rights will remain in poverty. On a global scale, those countries on the margins of the world system where disease and illness are rampant will be unable to ever equally enjoy the enormous amounts of wealth that characterize the world; it is the unequal distribution of that wealth that causes illness and that illness perpetuates.

Health is not only influenced by global economics, but also the social and cultural systems in which individuals live and which to a large degree determine daily life. Poverty, though, is still all too often the determining factor in who lives and who dies. Medical anthropology has done an excellent job of explaining how social and cultural forces shape health in societies throughout the world.¹⁵ Christopher Taylor gives an excellent example from Rwanda of the social and cultural understandings of health and illness and the relation to HIV/AIDS. Bodily fluids in Rwanda are understood in terms of “flow” and “blockage,” which are constantly adding to or detracting from the “fractal” person through human interactions.¹⁶ Flow is considered to be positive and pure, while blockage is negative and polluting. The exchange of bodily fluids during sexual intercourse in Rwanda is predicated on this understanding. When applied to contraception, condoms, in this cosmology, are seen as creating an unwelcome

¹⁴ Amartya Sen, *Development as Freedom* (New York: Anchor Books, 1999).

¹⁵ Hans A. Baer, Merrill Singer, and Ida Susser, *Medical Anthropology and the World System*, 2nd ed. (Westport, Connecticut: Praeger Publishers, 2003).

¹⁶ For example, look at Christopher C. Taylor, “Condoms and Cosmology: The ‘Fractal’ Person and Sexual Risk in Rwanda,” *Social Science and Medicine* 31 (1990), pp. 1023-1028.

“blockage” and destroying the “flow” of the sexual act. This deeply cultural conceptualization has a very concrete and negative impact on the use of condoms and, consequently, the efforts to halt the spread of HIV. Cultural practices, like unclean circumcisions and virginity testing, also have a great effect on health. These particular studies show the need for cultural respect and understanding, but the cultural effects on health are most clear in a nearly universal phenomenon: the marginalization and consequent powerlessness of women.

The devastating health outcomes experienced by marginalized women come to the fore when looking at reproductive health. The HIV/AIDS pandemic in sub-Saharan Africa shows that women are at a disadvantage both culturally and economically. Practices like widow inheritance, where women are passed on to a male family member of their dead husband (often from AIDS), spread HIV as well as entrench the inability of women to make their own sexual decisions. The cultural powerlessness of women to control condom use strips away protection from females who are already more physiologically vulnerable to sexually-transmitted infections. Social inferiority and the resulting poverty and lack of education experienced by many women results in “survival sex.”¹⁷ On an HIV prevention outreach program in Ghana, a young woman told how she had sex with an older man for money, knowing full well the dangers of AIDS; she needed the money as capital to start a hair-dressing business, and she knew that, as a woman, there was no other way to get it. HIV/AIDS hits women harder in part because of their cultural role as caretakers. Not only are they more vulnerable to becoming infected with

¹⁷ J. Wojcicki, “She drank his money: survival sex and the problem of violence in taverns in Gauteng Province, South Africa,” *Medical Anthropology Quarterly* 16 (2002), pp. 267-293.

HIV, but they are the ones who must care for those sick with AIDS and the orphans of those who have already died from it. The oppressive forces of gender discrimination structure women's vulnerability to illness.

What frameworks have been devised for understanding the social determinants of health, like economics and culture? Paul Farmer and other medical anthropologists suggest the perspective of “structural violence,” or the “violence of everyday life.” It leads to a greater understanding of individually embodied suffering by explaining that “suffering is ‘structured’ by historically given (and often economically driven) processes and forces that conspire—whether through routine, ritual, or, as is more commonly the case, the hard surfaces of life—to constrain agency.”¹⁸ Different “axes of oppression,” like gender, race, and especially poverty, help us to understand who is more like to experience social and physical suffering.

An even more comprehensive framework that builds on the concept of structural violence, is looking at the effects of “instability.” Fuller and Keenan explain that social marginalization is analytically inadequate when the entire fabric of vulnerable lives is defined by a lack of stability. They describe as unstable the lives of:

Those who are effected by civil strife, military incursions or liberation armies in Uganda, Haiti, Sudan, or the Congo; those who are refugees in any part of the world; those who are the victims of natural disasters; those in the prisons of Russia; those married to South African or Indian truck drivers who themselves live in very unstable worlds; those in debt-ridden nations on the verge of economic collapse; heads of families forced to migrate for employment, and those at home who await them; those who are drug addicts, whose own apprehension of themselves is itself unstable; those who are forced into sexual activity to support their children, their families, or their school fees; those who are overseas workers and fishermen; those who engage in clandestine homosexual activity in homophobic societies; or those girls and young women who are faithful to their marriages or to other stable sexual relationships but whose husbands or partners put them at risk because of external sexual liaisons.¹⁹

¹⁸ Farmer (2003), p. 33.

¹⁹ Fuller and Keenan (2005), p. 104.

Unstable lives defy simple categorization, but, in that way, the instability thesis is readily applicable to every individual and does not exclude any vulnerable person because of a narrow theoretical perspective. Looking at the social context of health and illness through the lenses of structural violence and instability gives one a much greater appreciation of the myriad factors that determine *why* a person is healthy or sick. Bioethicists in the developing world have suggested that the discipline will only serve the interests of all when it addresses the social realities of poverty, inequality, and all forms of instability.²⁰

HIV/AIDS and the Social Fault Lines

The HIV/AIDS pandemic is the definitive example of a disease determined by social forces. It overwhelmingly attacks the poor in the world's poorest nations, women where they are most powerless, and it makes a bee-line for those living in instability in the most unstable parts of the world. On a macro-level, the pandemic is "a reflection of a complex trajectory of social and economic forces that create widening global disparities in wealth and health."²¹ Instability and inequality in the global economic system ensures that those suffering from poverty anywhere, be it on the streets of New York City or the townships of South Africa, are at a greater risk of becoming infected with HIV and eventually dying from AIDS. The pandemic is woven into a complex embroidery that is at once tied to massive global forces and also to the most intimate areas of human

²⁰ Solomon R. Benatar, "Bioethics: Power and Injustice," *Bioethics* 17 (2003), pp. 387-398; Florencia Luna, "Poverty and Inequality: Challenges for the IAB," *Bioethics* 19 (2005), pp. 451-459.

²¹ Solomon R. Benatar, "The HIV/AIDS Pandemic: A Sign of Instability in a Complex Global System," *Journal of Medicine and Philosophy* 27 (2002), p. 163.

culture.²² The “exceptional” impact and challenges of the pandemic are underpinned by its being completely caught up in the social and economic currents of life.

Peter Piot enunciated the reasons why those who have had any experience with HIV/AIDS fear its unprecedented nature and are astounded that the response has, thus far, been low on the priority list of much of the world: “This pandemic is *exceptional* because there is no plateau in sight, *exceptional* because of the severity and longevity of its impact, and *exceptional* because of the special challenges that it poses to effective public action.”²³ Those who live in the world of AIDS and have felt its cold touch know all too well that humanity has never before experienced such a pandemic.

In this global era of interconnectedness and advancement in medical technologies especially, the world allows the HIV/AIDS pandemic to spread seemingly unchecked through the dependent and exploited developing countries. Sub-Saharan Africa, for example, is home to the majority of HIV-infected people, and the countries there have already borne the brunt of the millions of deaths AIDS causes each year.²⁴ If left unchecked, AIDS will only continue to claim lives in astronomical numbers. The true moral failure is that these deaths are largely preventable; the millions that have already occurred, and the many millions more that are forecast. A just and human response calls for a great deal of political will and collective action. It was this impetus that drove

²² Paul Farmer, *AIDS & Accusation: Haiti and the Geography of Blame* (Berkeley: University of California Press, 1992).

²³ Peter Piot, “Why AIDS is Exceptional,” London School of Economics (8 February 2005), available at <http://data.unaids.org/Media/Speeches02/SP_Piot_LSE_08Feb05_en.pdf>. Emphases mine.

²⁴ Martin Meredith, *The Fate of Africa: From the Hopes of Freedom to the Heart of Despair* (New York: Public Affairs, 2005).

Jonathan Mann to suggest that the language of human rights be used to discuss the public health and ethics of the HIV/AIDS crisis and global health more generally.

Introducing the Language of Human Rights and Social Justice

As a public health official working in the field of HIV/AIDS, Jonathan Mann was intimately aware of the social determinants of disease as well as the exceptional nature and the exceptional response required to fight the pandemic of our times:

To move forward, there must be a mixture of the pragmatic and the theoretical, and a blend of insight and practical experience. Once we have determined that for HIV/AIDS, as for all other health problems, the major determinants are societal, it ought to be clear that since society is an essential part of the problem, a societal-level analysis and action will be required. In other words, the new public health considers that both disease and society are so interconnected that both must be considered dynamic. An attempt to deal with one, the disease, without the other, the society, would be inherently inadequate.²⁵

Mann's great insight was to integrate medicine, public health, and bioethics by introducing the language of human rights:

Fortunately, entirely outside the domain of public health or biomedical science, a series of concepts and a framework for identifying the societal preconditions for health had been developed. The modern movement of human rights, born in the aftermath of the Holocaust in Europe and born of the deep aspiration to prevent a recurrence of government sponsored violence, provides AIDS prevention with a coherent conceptual framework for identifying and analyzing the societal root causes of vulnerability to HIV. It also provides both a common vocabulary for describing the commonalities that underlie the specific situations of vulnerable people around the world, and a clarity about the necessary direction of health-promoting societal change.²⁶

This seminal insight overcame disciplinary particularities in order to work towards the realization of health as a human right, which should be the goal of medicine, public health, and bioethics if they are guided by a spirit of justice.

This insight has had very concrete results for bioethics. The agenda is starting to shift, so that issues of health equity are being presented by an energetic minority of

²⁵ Jonathan Mann, "Human Rights and AIDS," Jonathan Mann et al., eds., *Health and Human Rights* (New York: Routledge, 1999), p. 222.

²⁶ *Ibid.*

bioethicists as a moral and disciplinary priority. It has also opened up dialogue with other traditions and other disciplines. Anthropologists, like Paul Farmer and others, have a coherent framework that makes possible an ethical discussion of the human right to health. Deans of the old school of bioethics are starting to accept the need for an ethics that can talk about the public health of communities, rather than just biomedical science as it concerns individuals.²⁷ So too have those in public health come to the realization that they must couple their longstanding pillars of community and social determinants of health with an investigation of how the priority of justice fits with these and calls for new ways of seeing public health action.²⁸ This shift in public health includes essential dialogue and overlap with bioethics.

Mann also extended his invitation to dialogue to other moral traditions, like the Roman Catholic one, in the spirit of the shared value of “human well-being.”²⁹ The work of Lisa Sowle Cahill has been ground-breaking in conceptualizing the human right to health and bioethical dilemmas with the Catholic principles of social justice and the common good.³⁰ Cahill has also helped to marry a social discourse of health with the Catholic tradition of justice: “AIDS is a justice issue, not primarily a sex issue. AIDS as a justice issue concerns the social relationships that help spread HIV and fail to alleviate

²⁷ Daniel Callahan and Bruce Jennings, “Ethics and Public Health: Forging a Strong Relationship,” *American Journal of Public Health* 92 (2002), pp. 169-176.

²⁸ Norman Daniels, “Why Justice is Good for our Health: The Social Determinants of Health Inequalities,” *Daedalus* 128 (1999), pp. 215-251; “Justice, Health, and Healthcare,” *American Journal of Bioethics* 1 (2001), pp. 2-16.

²⁹ Lawren O. Gostin, “Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann,” *Journal of Law, Medicine & Ethics* 29 (2001), pp. 121-130.

³⁰ Lisa Sowle Cahill, “Genetics, individualism, and the common good,” A. Holderegger and J.P. Wils, eds., *Interdisziplinäre Ethik: Grundlagen, Methoden, Bereiche* (Wien: Herder, 2001), pp. 378-392; *Bioethics and the Common Good* (Milwaukee: Marquette University Press, 2004); *Theological Bioethics: Participation, Justice, Change* (Washington, D.C.: Georgetown University Press, 2005).

AIDS, relationships of power and vulnerability that are in violation of Catholic norms of justice and the common good.”³¹ Jon Fuller and James Keenan explain how the pandemic and the language of human rights have dramatically remodeled bioethics into a discipline that truly works towards justice in healthcare.³² Their own work also goes a great distance in exploring how the Catholic tradition truly speaks to the HIV/AIDS pandemic, on issues like needle exchange programs, condom use, and the need for education and the virtue of mercy in a time of AIDS.³³ Mann’s call was also taken up by many different academic traditions and sub-groups, like feminist theorists and those looking for lessons for American bioethics in particular.³⁴

Though he introduced human rights as a common language of analysis, Mann’s ultimate goal was certainly not an analytical or academic one. Human rights was to become a language of *prescription* and a language of *action* to positively influence global health and to develop strategies that were effective in promoting health equity, rather than simply giving lip service to universal human values; the West has a long enough tradition of holding up human rights as moral obligations in name alone.³⁵ This calls bioethics not just to enunciate the values that we should hold dear, like health as a human right, but how we are morally obligated to look to their implementation. Thus, a language of

³¹ Lisa Sowle Cahill, “AIDS, Justice, and the Common Good,” James F. Keenan, ed., *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2002), pp. 282-293.

³² Jon D. Fuller and James F. Keenan, “The Language of Human Rights and Social Justice in the Face of HIV/AIDS,” *Budhi* 1&2 (2004), pp. 211-231; James F. Keenan, “Developments in Bioethics from the Perspective of HIV/AIDS,” *Cambridge Quarterly of Healthcare Ethics* 14 (2005), pp. 416-423.

³³ James F. Keenan, ed., *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2002).

³⁴ Rosemarie Tong, Anne Donchin, and Susan Dodds, eds., *Linking Visions: Feminist Bioethics, Human Rights, and the Developing World* (New York: Rowman & Littlefield, 2004); George J. Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries* (New York: Oxford University Press, 2005).

³⁵ Lori P. Knowles, “The Lingua Franca of Human Rights and the Rise of a Global Bioethic,” *Cambridge Quarterly of Healthcare Ethics* 10 (2001), pp. 253-263.

analysis reframes and rethinks the bioethical project and also gives a whole new solution: ensuring global health equity and the implementation of health as a human right in a spirit of social justice.

This solution answers the problem and challenge of bioethical failure in the case of organ sales. With the appropriate human rights language, the debate over an “ethical” market in organs would quickly be resolved, and bioethics would focus itself on areas of greater priority. One such area is the state of healthcare and the effects that the HIV/AIDS pandemic are having in South Africa, a little over a decade after the end of apartheid. First examining the social history of the patient and place will provide the appropriate context for attempting a human rights solution.

History of the Patient/Place: The Rainbow Nation

In 1994, landmark political and civil change came to South Africa. After 46 years of apartheid rule, Nelson Mandela became South Africa’s first democratically elected leader. With political and civil freedom for the first time in generations, the African majority, oppressed and exploited since the arrival of the first Europeans in the fourteenth century, felt a new, nearly boundless optimism. They thought it only natural, only just, that the country’s resources be put in their hands. After generations of apartheid rule, they would be able to live in better conditions than the ones that they had known in the shantytowns and townships surrounding the urban centers of white privilege. There would be electricity, running water, education, food, and healthcare. There was no lack of political will: Mandela and his African National Congress were from and for the exploited African majority. At the core of the struggle against apartheid was the yearning

for social and economic rights, and it was expected that they would be afforded to millions who had never known them before. Without social and economic progress, the civil and political gains of the early 1990s would represent only so many empty promises.

Unfortunately, the “New South Africa” ran smack into a global capitalist economic system flexing its muscles after the fall of the Soviet Union. With empty coffers courtesy of the bankrupt apartheid state and an international community that turned its back once talk came to social and economic rights, South Africa’s only opportunity for growth was to play by the economic rules set by the neo-liberal Western powers. The struggle against apartheid was for rights of human beings, widely construed: civil and political rights as well as social and economic rights. Ideologically, the West, in its push for democratization, had much to say about the former set of rights. Economically, however, Western faith was in a free market system, and it was up to the newly democratic South Africa to achieve social and economic rights on its own, on a very unequal playing field.

International capitalism requires a small corps of highly skilled workers that can flexibly meet the demands of the international market while manipulating its advanced technology. Apartheid could not have set the poor black majority up for failure in this system any better. For generations, it had deliberately crippled the black workforce with inferior education and a tight hold on all access to economic skills. By apartheid’s design and policy, South Africa’s black majority was meant to provide a huge pool of cheap unskilled labor to mine gold and diamonds and otherwise serve the white minority. The apartheid state realized this “objective” quite effectively, so that by 1994, the workers

best suited to integration in the global capitalist arena were those who benefited most from the apartheid policies of segregation: mostly whites and a sprinkling of the other “races.”³⁶

The economic inequality that defined South Africa during the apartheid years has continued into its democratic era. Alistair Sparks, a South African journalist who has provided keen social insight for many years, describes the economy of post-apartheid South Africa as a double-decker bus.³⁷ The upper deck is the small, racially-integrated, highly skilled workforce that can compete in international capitalism and that profits from it. The lower deck is the majority of the population: poor, black, and unskilled (in economic terms). It is extremely difficult to get from the lower to the upper deck, and it is certainly impossible to do so on a widespread scale without social and economic change. Regrettably, Sparks’s economic analysis holds true for an analysis of South African society on the whole.

For those who live in South Africa, there are two worlds. To borrow development discourse, there is a small and isolated developed world comprised of the major urban centers and tourist refuges. The rest of the country, home to the vast majority of South Africans, is part of the developing world, and it lags far behind socially and economically. A long history of structural violence and instability has decided who belongs to which world. For the few, it is possible to receive an exceptional education

³⁶ Many commentators have noted the spuriousness of the concept of “race.” According to Paul Farmer, the term was constructed by the West and is “technically incorrect and historically tendentious.” Paul Farmer, “If We Fail to Act,” *Notre Dame Magazine* Autumn 2006, p. 23. The term is particularly absurd in South Africa, where the plurality of categories made racial assignment an arbitrary task.

³⁷ Alistair Sparks, *Beyond the Miracle: Inside the New South Africa* (Chicago: University of Chicago Press, 2003).

and world-class private healthcare while enjoying political and economic power (or, in fact, because of it). Or, instead of this closely-guarded luxury, one can live as the majority does, in shantytowns or neglected rural areas with few basic utilities, jobs for less than half of the labor force, and decidedly poor education and healthcare if one gets any at all. The only certainties are crime, poverty, AIDS, and the crushing knowledge that one will never get the same advantages that are enjoyed by the privileged minority, just a twenty minute drive away.

The apartheid system may be dead politically, but it has only been replaced by social and economic apartheid. Desmond Tutu, the Nobel Peace Laureate, head of the Truth and Reconciliation Committee, and something akin to the spiritual and moral leader of the country put it well: “Unless houses replace the hovels and shacks in which most blacks live, unless blacks gain access to clean water, electricity, affordable health care, decent education, good jobs, and a safe environment...we can just as well kiss reconciliation goodbye.”³⁸ His remarks referred to the process of reconciliation, but they can more generally be applied to the entire project of creating a new, vibrant, and humane post-apartheid South Africa.

Handicapped by the global capitalist system that it was forced into and with no concerted international effort to ensure social and economic rights, the South Africa government is struggling to allocate resources to its poor. Still overwhelmingly Mandela’s African National Congress, it has fought to bring change with affirmative action business programs as well as with health and educational service outreach

³⁸ Desmond Tutu, *No Future Without Forgiveness* (New York: Doubleday, 1999), p. 274.

programmes. In the 1990s, Mandela tried and failed to make access to housing, water, and electricity a reality for every South African. With empty state coffers and little economic growth, almost all of the ambitious social programs put in place after 1994 fell short and were abandoned. Like most other developing nations, South Africa found that its pleas for socio-economic progress fell largely on deaf ears. Some handouts in foreign aid and a multitude of NGOs were little more than a bandage on the country's gaping wound.

Nowhere are South Africa's social and economic needs more apparent than in the area of healthcare. When South Africa is mentioned, HIV/AIDS immediately comes to the mind of even the most casual international observer. Indeed, AIDS is, for some, the only thing that comes to mind at the mention of the country (and the continent as well). In a nation of 44 million people, over one-fifth of the adult population is estimated to be infected with HIV, and a full 11% of the population on the whole.³⁹ This tremendous burden of disease negatively impacts almost all aspects of South African life, and it is a symptom of the great poverty and inequality which mark the country today. It is also a product of the country's complicated and troubled history.

The epidemic history of South Africa is essential to addressing the HIV/AIDS epidemic in the country today. As Howard Phillips explains, "Disease mediates social relations. This is even more the case if a disease develops an all-threatening virulence and assumes epidemic proportions."⁴⁰ The popular discourse around the HIV/AIDS

³⁹ CIA World Factbook for South Africa accessed on December 3, 2006 at <<https://www.cia.gov/cia/publications/factbook/geos/sf.html>>.

⁴⁰ Howard Phillips, *'Black October': The Impact of the Spanish Influenza Epidemic of 1918 on South Africa* University of Cape Town Thesis, Department of History, 1984, pp. 1-2.

epidemic assumes that the disaster is a wholly unprecedented one, increasing the stigma and general sense of hopelessness associated with the “death sentence” of AIDS. The epidemic history, however, shows that HIV/AIDS is with and without precedent.⁴¹ In that sense, it serves to reveal the origins of the epidemic, the forces that shaped it, and the ways to overcome it.

Two major themes come to the fore in studying South Africa’s epidemic history: the “long pedigree of blaming the victim” and the role of migrant labor in spreading disease.⁴² The social “othering” evident in the HIV/AIDS epidemic in South Africa (as well as many other regions in the world) has a long tradition in South Africans’ responses to illness. It both encouraged and grew out of the deep racism that defined the country for many years. In an outbreak of bubonic plague at the turn of the twentieth century, segregation of Black Africans was initiated both on the grounds of contemporary understandings of sanitation and disease, and because they themselves were seen as “the social pest...spreading like an epidemic...undermining all sense of security.”⁴³ This social and cultural differentiation underpinned the ideologies of racism and apartheid that plagued South Africa for decades, and it would continue to do the same for the country’s most recent epidemic.

One of the most harmful yet fundamental elements of the social response to HIV/AIDS is the stigma that is attached to it. It was initially stigmatized in the 1980s as a

⁴¹ Howard Phillips, “HIV/AIDS in the Context of South Africa’s Epidemic History,” K.D. Kauffman and D.L. Lindauer, eds., *AIDS and South Africa: The Social Expression of a Pandemic* (New York: Palgrave Macmillan, 2004).

⁴² *Ibid.*, p. 33.

⁴³ Maynard W. Swanson, “The Sanitation Syndrome: Bubonic Plague and Urban Native Policy in the Cape Colony, 1900-1909,” *Journal of African History* 18 (1977), p. 391.

disease of homosexuals, prostitutes, and IV drug users. As the disease spread to the young African population of South Africa, the stigma shifted to that group accordingly. The reaction by the apartheid regime to the epidemic clearly parallels the reactions by the white populations during previous outbreaks of disease, as with the bubonic plague or Spanish Influenza. Virginia van der Vliet described the white South African population in the last years of apartheid as trying to maintain their health as a closed community in a sea of AIDS.⁴⁴ This perspective has done little to address the root causes of the epidemic, which in fact lay in the policies of the apartheid state.

One of the most destructive policies of apartheid was to separate a great many African men from their families, in order to use them as migrant laborers. Women, children, and the elderly were relegated to contrived “native homelands,” while the fathers and husbands were sent to labor camps to work the diamond and gold mines, or to otherwise serve the white minority. Kept away from home for months, the men in the migrant labor camps would turn to prostitutes to fill the sexual void. Sexually transmitted diseases moved from the camps to the homelands and back again, driven by the need of the apartheid state to access to a large and mobile labor pool.⁴⁵ The economic policies of the apartheid state fueled the spread of HIV within South Africa and between other southern African nations. The effects of migration are of course social and cultural as well as economic, destroying families and convoluting social values.⁴⁶

⁴⁴ Virginia van der Vliet, “AIDS: Losing the ‘New Struggle’?,” *Daedalus* 130 (2001), pp. 151-184.

⁴⁵ Anne-Christine D’Adesky, *Moving Mountains: The Race to Treat Global AIDS* (New York: Verso, 2004), pp. 189-205.

⁴⁶ Stuart C. Bate, “Differences in Confessional Advice in South Africa,” James F. Keenan, ed., *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2002), pp. 212-221.

Addressing the history of social and economic inequality in South Africa and its direct effects of negative health outcomes (especially when looking at AIDS) requires a discourse centered on the provision of healthcare as a human right. Social movements, growing out of the tradition of anti-apartheid activism, are now beginning to mobilize around health. Their pleas are deeply impassioned and morally convincing, showing how the new model of bioethics translates into political action on a local scale. The Treatment Action Campaign's push for access to antiretroviral treatment for all those afflicted with AIDS in South Africa is an excellent example of how the new proposal for bioethics makes possible great achievements when put into action.

3. Achievement in the Face of AIDS

AIDS is above all a remediable adversity. Our living and our life forces are stronger, our capacity for wholeness as humans is larger, than the individual effects of the virus. Africa seeks healing. That healing lies within the power of our own actions. In inviting us to deal with the losses it has already inflicted, and, more importantly, in enjoining us to avoid future losses that our own capacity to action make necessary, AIDS beckons us to the fullness and power of our own humanity. It is not an invitation that we should avoid or refuse.

Edwin Cameron, South Africa's first publicly open HIV-positive official¹

The proposal for a new bioethics premised on human rights and social justice is as much a challenge as it is a solution. It is no exaggeration to say that working towards the provision of health care as a human right is a Herculean task; most would in fact describe it as an impossible one. A new health activism reminds us, however, that whether or not the ultimate goal of health equity is a realistic one, the important thing, now, is to move closer to that ideal. The Treatment Action Campaign is one of the strongest examples of what can be achieved by not backing down from the stance that *health is a human right*, even in an AIDS epidemic as disastrous as South Africa's.

To make no secret of their basic foundation, the Treatment Action Campaign (from here on out, TAC) began on International Human Rights Day in 1998, with only fifteen activists. By the end of the day, they had over a thousand signatures from passersby in Cape Town, South Africa, who agreed that antiretroviral (ARV) treatment should be available to every person in the country for whom it was medically indicated (no small number, even in 1998). The spirit of TAC is inextricably linked to the passion of its founder and the very basic and very human response that led him to start the organization. Zackie Achmat is an HIV-positive former male prostitute and a seasoned

¹ Edwin Cameron, *Witness to AIDS* (New York: I.B. Tauris, 2005), pp. 214-215.

activist with experience in the anti-apartheid struggle and the push for gay rights in South Africa. He announced the beginning of TAC at the funeral of his friend, Simon Nkoli, who died because he could not afford ARVs.² Zackie challenged the perverse logic that said some people in the world (mostly those in wealthy countries) and some people in South Africa (mostly the wealthy and the powerful) could get treatment for AIDS and its opportunistic infections while others could not.

This impassioned beginning would draw more and more activists to the cause of access to ARVs as a human right. Some came from the ranks of anti-apartheid and gay rights movements, while many were poor black women whose lives were the ones most directly impacted by the virus; either they had it themselves, or they were the caretakers of those who were dying from it.³ Though Zackie's personality was a major part of TAC and the AIDS movement as a whole in South Africa, the strength of the moral plea for access to ARVs became the backbone of the organization. Their framework was decidedly in the mold that Jonathan Mann had envisioned: one rising up out of the language of human rights, but ending in action, rather than just analysis. As the TAC activist Nathan Geffen describes: "For us, a human rights framework is not merely an academic tool, but the fundamental basis of our advocacy."⁴

In 1999, Achmat would live the reality of those he was fighting to gain access for. He embodied the equality of human life when he refused to go on ARVs himself until all

² Samantha Power, "The AIDS Rebel," *New Yorker* (19 May 2003), p. 54.

³ Steven Friedman and Shauna Mottiar, "A Moral to the Tale: The Treatment Action Campaign and the Politics of HIV/AIDS," (University of KwaZulu-Natal: Centre for Policy Studies, 2004), available online at <<http://www.nu.ac.za/ccs/files/Friedman%20Mottier%20TAC%20Research%20Report%20Short.pdf>>.

⁴ Stephen P. Marks, "The Evolving Field of Health and Human Rights: Issues and Methods," *Journal of Law, Medicine & Ethics* 30 (2002), pp. 739-754.

South Africans could obtain it in the public health system.⁵ Much of TAC's activism has been both successful and powerful because of the ingenuity of its members coupled with the undeniable moral strength of its appeal. The issue that TAC mobilized around could not be a more important or more pressing one in South Africa, and, in a very real sense, the moral obligation to address access to ARVs chose them.

TAC expected to be primarily squaring off against the powerful and profitable pharmaceutical industry that kept drug prices out of the common person's reach. In late 2000, they mounted a campaign against the pharmaceutical company Pfizer, seeking to wrest monopoly control over life-saving drugs from big business: "The defiance campaign demonstrated TAC's uncompromising determination to increase access to life-saving medicines for poor people. The group decided to consider importing generic fluconazole into South Africa in defiance of Pfizer's patent rights."⁶ Achmat and another activist personally carried thousands of doses of generic drugs into South Africa on a flight from Thailand. Though illegal, their actions would garner a great deal of media attention and public support, eventually humbling Pfizer and other drug companies into making substantial donations of the much-needed medicines. The Pharmaceutical Researchers and Manufacturers of America (PhRMA) was forced by pressure within South Africa and internationally to withdraw a lawsuit it had filed against the South African government who had followed the lead of Brazil and ignored patent rights in

⁵ Power (2003). Achmat would finally give up this gamble in March 2003, with his CD4 counts dangerously low and the prospect of universal access, at least in name, not far off.

⁶ Cameron (2005), p. 163.

order to allow the use of generic drugs.⁷ TAC's insistence that access take priority over profits won the day, and it was their appeal to human rights that led to their victory in the court of internationally opinion.

Ironically, the pharmaceutical industry did not prove to be TAC's toughest adversary. Soon after ARVs became increasingly available in South Africa, TAC found that the lack of political will in the government towards fighting AIDS was their biggest obstacle. The surest way to effectively counter the HIV/AIDS pandemic on a national scale has been with a great deal of support from the highest levels of government. In Brazil, a country with tremendous inequality like South Africa, the government made universal access to ARVs a reality by manufacturing their own generic drugs. Uganda is also one of the pandemic's success stories, with a large reduction in rates made possible by the president make HIV prevention and AIDS treatment his top priority.⁸ The magnitude of South Africa's epidemic makes political will even more important, but TAC found that political resistance rather than support came directly from the top, in the person of President Thabo Mbeki.

The dissident science of AIDS denialism appealed to Mbeki, a renowned Third World intellectual and who learned his distrust of Western hegemony in the struggle against the apartheid regime. He believed the connection between HIV and AIDS to be a fallacy meant to dehumanize the African and ignore the poverty that was making his

⁷ Barbara A. Noah, "AIDS and Antiretroviral Drugs in South Africa," *Journal of Law, Medicine & Ethics* 31 (2003), p. 144.

⁸ D'Adesky (2004).

people sick.⁹ Ironically, Mbeki's response was a misguided application of some of the themes of a health and human rights discourse. He saw that it was poverty and social forces that explained why South Africans were becoming sick, but he missed the biological role of HIV and AIDS is becoming embodied as social suffering. His response was also conditioned by a wariness of the legacy of Western de-stabilization that had long kept stable societies willfully ignorant of and complicit in health inequalities. But Mbeki's analysis was thrown off by a misguided cultural politics of race and nationalism:

Mbeki's 'African nationalist' response to the AIDS pandemic illustrates the workings of a cultural politics of identity that diverted attention from working-class and poor people's struggles for access to life-savings AIDS treatment that are accessible to the middle classes. The responses of African nationalists and dissidents within government and the ruling party clashed with the class-based mobilization of AIDS activists and trade unionists who insisted that ARVs be made freely available in public health facilities as part of citizens' constitutional rights to health care.¹⁰

Conditioned to be defensive in the face of Western imperialism, Mbeki spent crucial years of the epidemic trying to disprove the link between HIV and AIDS and making sure that South Africa's health system remained wary of ARVs.

The result was a failure by the Ministry of Health to implement ARV treatment programs on a widespread scale, even when pharmaceutical companies like Boehringer-Ingelheim were offering free drugs and when South Africa's own licensing board approved the drugs for use. The success of treatment programs, like that of *Médecins Sans Frontières* (MSF), in some of the worst townships, like Khayelitsha, where there was little health infrastructure and resources were callously ignored instead of

⁹ Steven Robins, "'Long live Zackie, long live': AIDS activism, science, and citizenship after apartheid," *Journal of Southern African Studies* 30 (2004), pp. 651-672.

¹⁰ *Ibid.*, p.670.

duplicated.¹¹ Nothing is more effective in fighting the HIV/AIDS pandemic and other health challenges than an abundance of political will. South Africa found that the reverse is also true: nothing is more devastating to the HIV/AIDS fight than political resistance to realizing health as a human right. TAC, amazed that they had to struggle against the same government that they spent the apartheid years being arrested, jailed, and beaten to put into power, concluded that they would have to resist Mbeki and the Ministry of Health.

The civil and political gains of the anti-apartheid movement gave TAC the opportunity to mingling new forms of resistance with the time-tested tactic of civil disobedience. With the judiciary now in place to ensure their rights, social and economic as well as civil and political, TAC was able to use the courts as a resource where it had been a mechanism of oppression during apartheid. TAC initiated a lawsuit against the Minister of Health, alleging that the failure by the government to make nevirapine widely available to pregnant HIV-positive women was a systematic violation of the social and economic right to health, protected in the South African Constitution. The drug was free and had the potential to greatly reduce mother to child transmission of the virus. The court case would be a dramatic turning point for the global realization of health as a human right.

Victory in the Constitutional Court

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and *medical care* and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

¹¹ Renee C. Fox and Eric Goemaere, "They Call It 'Patient Selection' in Khayelitsha: The Experience of Medecins Sans Frontieres-South Africa in Enrolling Patients to Receive Antiretroviral Treatment for HIV/AIDS," *Cambridge Quarterly of Healthcare Ethics* 15 (2006), pp. 302-312.

South Africa's Constitution is unique in that social and economic rights are enshrined in law, rather than just being a matter of non-binding international law that nation-states routinely ignore. The progressiveness of the Constitution was both a response to the domestic history of apartheid as well as the global historical context of the fall of Communism; South Africa sought to blend the civil and political rights that had been the U.S. domain with the social and economic rights characteristic of the Soviet Union. When writing the new Constitution in 1994, the framers looked to the International Covenant on Social and Economic Rights, then, in an effort to blend it with the more strictly political rights that were a Western preserve.¹³ In this way, South Africa became one of the first and is still one of the only countries in the world to have binding universal fundamental rights in the spirit of the modern human rights movement. This proved crucial to the TAC case and the fight for ARVs.

Presented with a decision by a lower court that ordered the government to take “reasonable” steps to “progressively realize” the right to health as enshrined in the Constitution, South Africa's Constitutional Court (equivalent to the U.S. Supreme Court) issued a ruling in TAC's favor that shows what can be achieved legally by employing a human rights framework to health:

The Constitutional Court's order declared that sections 27(1) and (2) required that the government devise and implement a comprehensive program to realize progressively the rights of pregnant women and their children to have access to health services to prevent mother-child transmission of

¹² “Universal Declaration of Human Rights,” accessed on December 3, 2006 at <<http://www.unhcr.ch/udhr/lang/eng.htm>>. Emphasis mine.

¹³ Joan Fitzpatrick and Ron C. Slye, “Republic of South Africa v. Grootboom and Minister of Health v. Treatment Action Campaign,” *The American Journal of International Law* 97 (2003), p. 673.

HIV. The order further required that the program include testing and counseling. Finally, the government was required to remove restrictions on dispensing nevirapine at public hospitals and clinics where medically indicated; to make provision, if necessary, for training counselors at public hospitals and clinics; and to take reasonable measures to extend testing and counseling facilities throughout the public health sector.¹⁴

In some senses, the ruling raises more questions than it answers. But, ultimately, it says that health is a human right and the government has a responsibility (conditional) to realize it for its citizens. The decision also makes clear that the right is a communal one: individuals cannot expect that the government provide services to them on demand. The ruling also makes a preferential option for the society's most vulnerable, following the ideology of the common good and social justice. TAC's victory was nothing short of stunning; not only did the Court rule that nevirapine be made widely available, it also spurred the government to begin implementing a program to provide ARV treatment throughout the country's public health facilities. It also brought the right to health and the right to treatment to the attention of the international community and signified a shift in the way the world sees the provision of social and economic rights.¹⁵

TAC's Social Victories

Coupled with their legal and material victories is the effect that TAC has had on the social sphere surrounding HIV/AIDS in South Africa. Through education and awareness campaigns, TAC has greatly reduced the stigma that fueled the South African epidemic as it does across the world. It is also argued that the struggle for care and the treatment it has won are having extremely positive effects on the psyche of those with the

¹⁴ Fitzpatrick and Slye (2003), p. 675.

¹⁵ Leslie London, "Human Rights and Public Health: Dichotomies or Synergies in Developing Countries? Examining the Case of HIV in South Africa," *Journal of Law, Medicine & Ethics* 30 (2002), pp. 677-691.

illness as well as the perception of the infected; it has also cultivated a health citizenship that can mobilize to make further gains.

The “HIV POSITIVE” t-shirt campaign initiated by Zackie Achmat is the most visible manifestation of the social effect that TAC has had:

It has become far beyond South Africa’s borders a symbol of the struggle for justice and reason and openness in the AIDS debate. It is worn casually and widely by many thousands of people—positive and negative—in marches, on the street, at work, and at home. It has done more to lessen stigma than innumerable speeches and workshops and think-tanks. It says, as the Danish king did in the fable of the yellow star during the Nazi persecution of the Danish Jews: we all bear this condition. We are all HIV POSITIVE. We all need treatment to be made available.¹⁶

The effects of stigma are some of the pandemic’s most insidious, making people loathe to access treatment even where it is freely available. TAC has done a great deal to reduce this stigma in South Africa, though there is a long way to go until there is complete openness. Steven Robins, an anthropologist, describes how the road may be made shorter by the new “health citizenship” and positive life space created by TAC’s activism and gains in treatment.

Essentially, Robins argues, the “social death” of stigma and the late stages of AIDS bring sufferers to the brink of death which ARVs can bring them back from, giving them hope and “new life.” He uses ritual analysis to describe how this commits TAC activists to social change and activism, as well as a positive space within South African society to pursue rights-based struggles. This new citizenship is deeply tied to both human rights and the embodiment of extreme suffering and recovery.¹⁷ Looking at

¹⁶ Cameron (2005), pp. 129-130.

¹⁷ Steven Robins, “From ‘Rights’ to ‘Ritual’: AIDS Activism in South Africa,” *American Anthropologist* 108 (2006), pp. 312-323.

TAC's achievements with a social lens gives an even broader view of their positive impact on South African society and the struggle against HIV/AIDS.

An Ethics of Implementation and Action

The difference between what we do and what we are capable of doing would suffice to solve most of the world's problems.

Mahatma Gandhi

The aftermath of the Constitutional Court decision of 2002 highlights the extremely difficult challenges that are necessarily faced when implementing widespread health reforms, especially in the developing world. The wording of the decision itself raised complicated questions: what was the government obliged to do to carry out “progressive realization” of access to ARVs and healthcare more generally? What would be considered “reasonable” steps in this direction? The Court made some concrete directions, but left the government to decide what was possible within its “limited” resources. With this, we return to the primacy of economics and the renewed importance of a human rights discourse to set moral priorities.

Nicoli Nattrass, an economist at the University of Cape Town, provides the best investigation of the “moral economy of AIDS” in South Africa.¹⁸ She describes the discourse of “unaffordability” within a framework of “moral triage” that is characteristic of many global health debates but especially the one around HIV/AIDS care in South Africa. Saving the lives of those needing treatment plummets down the priority list vis-à-vis prevention (a false opposition, since treatment and prevention are complementary) as well as the other expenses the state has. Nattrass argues that hiding behind the rhetoric of

¹⁸ Nicoli Nattrass, *The Moral Economy of AIDS in South Africa* (New York: Cambridge University Press, 2004).

limited resources is a thin veil for the many moral judgments that must accompany a decision not to provide ARV treatment. It involves an inherent devaluing and dehumanizing of those vulnerable people who contracted HIV and cannot afford to pay for their own care. Most importantly, Nattrass's economic models show that, in the long run, treating those with AIDS will be economically beneficial considering their contribution to the workforce as well as the decreased costs of treating the opportunistic infections that they would have had.

The argument for treatment belies the slow ARV rollout that has followed the decision of 2002. With the legal battle won, TAC has had to pressure the government a great deal to finally come out with a comprehensive ARV program. The most recent plan, for 2007-2011 is the most progressive yet, but it took five years to get to it, and universal care is still quite far from being realistic.¹⁹ Having obtained access to ARVs in name and with a good deal of goodwill donations from pharmaceutical companies, TAC and South Africa are confronting the lack of health infrastructure characteristic of most of the developing world as well as a "rationing" rhetoric that silences the language of human rights.

TAC's successes came mainly in the three urban provinces of South Africa, and that is also where successful treatment programs have been set up. Rural health infrastructure is severely lacking, with facilities few and far between and health personnel nearly non-existent. The "brain drain," sucking publicly trained doctors away from South Africa and other developing countries to work for much higher pay in the industrialized

¹⁹ Peter Greste, "South Africa has launched an ambitious five-year plan to combat AIDS," *BBC News* at <bbc.co.uk/news>, (14 March 2007).

world has had an effect that a new mandatory service year for graduating doctors has barely addressed. The question now is: what can TAC do to ensure implementation of their rights-based victory? Does their model have the potential for action on a wider scale, and is it a sustainable model?

The answer seems to be that TAC faces great challenges, but not insurmountable ones. As for the organization itself, its self-governance is such that it does not rely overly much on the personality of Zackie Achmat to maintain its activism and life. Its new magazine, *Equal Treatment*, gives the poor and powerless a voice that they never had before.²⁰ A democratic structure and increasing roles for women and the poor within the organization ensure that TAC will share in South Africa's new life. It has also taken important steps to realize similar rights-based advances throughout the sub-Saharan African region.²¹ The health as a human right model is taking hold in South Africa and elsewhere. Material gains usually amount to an impressive first step, but true health equity is a long way off.

Bioethics's role must be to provide an "ethics of implementation" that stresses action and results.²² The language of human rights is a language of ideals. As we have seen, it is important to voice as a universal ideal, but change will not come all at once. There must be a certain degree of pragmatism, one that does not accept things as they are, and still struggles to change them. A dangerous discourse that has arisen in the face of

²⁰ "Making HIV Prevention Work," *Equal Treatment* November 2006, available online at <tao.org.za>.

²¹ Friedman and Mottiar (2004).

²² Stuart Rennie and Frieda Behets, "AIDS Care and Treatment in Sub-Saharan Africa: Implementation Ethics," *Hastings Center Report* 36 (2006), pp. 23-31.

global health challenges is that of “rationing”.²³ It hides behind the veil of limited resources, just like “unaffordability”, to say, essentially, that what we are doing is all that we can do. It makes those in the developed and stable world, who are perpetuating this discourse, feel that they have met their moral obligations, while it forces those in the developed world keep quiet for fear that they will lose what little they already have.

Successful programs, like MSF in Khayelitsha, and Paul Farmer’s Partners in Health Group in Haiti, have shown that “rationing” is a counterproductive discourse. One must maintain the radical ideal of health equity, while only allowing the true constraints of no money and no resources to set limits to a project. But this is still unacceptable. One must use the language of human rights to keep the moral pressure on those in leadership and those with resources to give it as a moral obligation. Health equity must always be the goal, even if the powerful would like to pass it off as “unrealistic”. Thus far, these programs have remained small, but their numbers are growing. TAC has shown in South Africa what it is possible to achieve with a humble start, and they continue to work, keeping in mind the implementation challenges in South Africa.²⁴

To fight for health equity, bioethics must make a substantial shift towards examining health inequalities across the world from a social and public health perspective. Using the language of human rights, it must be radical in its advocacy of new moral priorities in health. This seems like a difficult task, given resource and infrastructure constraints, but one statistic puts in perspective how skewed the world’s

²³ Sydney Rosen, et al., “Hard Choices: Rationing Antiretroviral Therapy for HIV/AIDS in Africa,” *Lancet* 365, pp. 354-356.

²⁴ Solomon R. Benatar, “Health Care Reform and the Crisis of HIV and AIDS in South Africa,” *New England Journal of Medicine* 351 (2004), pp. 81-92; Fox and Goemaere (2006).

priorities really are and how much is really available to achieve the goal of health equity: last year, spending on veterinary care for pets in the United States was \$9.4 billion.²⁵ Conversely, for the “exceptional” pandemic of HIV/AIDS, infecting, killing, and effecting millions outside of the United States, a paltry \$8.3 billion was spent across the globe.²⁶ Global society must interrogate its priorities, and a socially contextualized and human rights-oriented bioethics has a great role to play in this. By stressing action and implementation, bioethics will help to make the universal value of health and well-being a reality for all. But how long will it take until we truly consider every human life to be equal?

²⁵ The total pet spending was even more troubling; a whopping \$38.4 billion. Online at <http://www.appma.org/press_releasedetail.asp?id=84>.

²⁶ Accessed at <www.unaids.org>.

Conclusion: An Ethics of Implementation

The great inequalities in global health that allow some to die preventable deaths while others receive too much advanced biomedical care must be erased. Bioethics, as first conceived in the West, is not just inadequate in erasing global inequalities but serves to manage them by obfuscating the issues of greatest moral priority. Instead of focusing on the issues facing the poor children of the developing world who lack food and healthcare, the first model of bioethics is content to debate the rights of the unborn in the developed world. When it does address the plight of the suffering and powerless, bioethics, as in the case of organ sales, often stands on the side of those perpetrating injustice, rather than those working against it. The new bioethical paradigm that has emerged from the crucible of the HIV/AIDS pandemic and social realities seeks and achieves to redress the harm of the first model as well as the greater issues of inequality in health.

Reflecting on the successes of movements like the Treatment Action Campaign, one questions what steps must be taken to broaden the push towards global health equity. Small, passionate campaigns have brought the human rights agenda into the public consciousness by carrying the torch of radical ideals. This initial impetus is essential to change, but it alone cannot succeed. Countless examples, especially in the AIDS fight, show that it is political will at the highest levels that is needed to achieve a complete society-wide response. There have been positive intermediate steps like the President's Emergency Plan For AIDS Relief (PEPFAR), that have built on the initial idealist push by human rights advocates. But the moral urgency of preventable suffering worldwide

obligates us to find effective and thorough interventions that are much more than a bandage on the gaping wounds of structural violence and instability. Deeply committed social responses require an ethics that sustains the initial moral appeal of health as a human right. An ethics of implementation is the next tool in the fight for global health; it challenges a cosmopolitan world not just to voice the value of health equity, but to realize it.

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