## STUPID DEATHS

## A Review of Paul Farmer's Pathologies of Power

In <u>Pathologies of Power</u> Paul Farmer examines the violence structured into the very structures of our society. Using as examples his visits to a tuberculosis epidemic in Russian prisons and his own work with AIDS in Haiti, Farmer guides us clearly through the terrain and gives us some sense of how we should begin.

The majority of premature deaths [worldwide] are, as the Haitians would say, 'stupid deaths.' They are completely preventable with the tools already available to the fortunate few. ... [T]hese deaths are a great injustice and a stain on the conscience of modern medicine and science. Why, then, are [they] not the primary object of discussion and debate within our professional circles? (p 144)

In 2002, 300 of the sickest AIDS patients in a clinic's care began receiving Highly Active Anti-Retroviral Therapy (HAART) through the HIV Equity Initiative. The treatment group has since expanded to 450. Of the patients currently under treatment, a majority has achieved undetectable viral loads. Despite their disease, they live normal, active lives. In itself, this is not surprising since HAART is, after all, "highly active." What makes the HIV Equity Initiative remarkable, all would probably agree, is its location: the rural Central Plateau of Haiti, the poorest country in the Western Hemisphere. Physician Paul Farmer and his colleagues at Partners in Health, who established their clinic in Haiti over twenty years ago are demonstrating that even within an extremely poor and oppressed population, AIDS, tuberculosis, and their many complications can be successfully treated.

But why do we consider the HIV Equity Initiative so remarkable? Farmer and his colleagues are not really pioneering new treatment regimens. Their "Directly Observed Treatment" (DOT)—in which a member of the health care team actually observes patients taking their medications—is well known from TB treatment. For those working in poor areas of the world, Farmer's use of trained community health workers to do most of the continuing care and follow up is hardly an innovation. HAART has been well documented to stop the progression of disease in many patients and restore them to a relatively normal life.

So the project contains in itself few innovations. What makes it remarkable, it seems, is that the poorest people in the West are receiving the same treatment that is available to the rest of us. Simple justice, it seems, is remarkable.

In 1948, the General Assembly of the United Nations passed the Universal Declaration of Human Rights, which included rights to food, clothing, shelter, education, and health care. Yet today we consider it "remarkable" that a small group of impoverished Haitians would receive medical treatment that is standard for most citizens of industrialized nations. We accept the severe violation of the social and economic rights of the majority of world citizens as normal and acceptable.

Living in an Unjust World

"How can we come to terms with ... the most basic privation from which human beings can suffer? Do we see it simply as a human predicament—an inescapable result of the frailty of our existence? That would be correct had these sufferings been really inescapable, but they are far from that. Preventable diseases can indeed be prevented, curable ailments can certainly be cured, and controllable maladies call out for control. ... [W]e have to look for a better comprehension of the social causes of horror and also of our tolerance of societal abominations." (p xii)

We live in an unjust world. Its economic, social, political, and military order confers affluence upon a minority of us, poverty on most, and penury upon a good billion. This poverty and penury are not relative terms but absolute conditions that, for instance, kill 25,000 children a day, consign millions to death by AIDS, and make the median age at death in sub-Saharan Africa five years. [1] Most of us think about this, at least briefly, from time to time. How do we make sense of the reality that millions of people suffer and die every year from utterly preventable deaths—what the Haitians call "stupid deaths"—while others of us live in a surfeit that could easily relieve the worst of the suffering? How do we think about the economic, political, and social systems that have bestowed upon most of us privileges of wealth and power while those very same systems are directly responsible for the suffering and deaths of countless people in our own countries and around the world? Why, in other words, do we, the privileged, accept our privileges when they derive from structures that maim and murder others? Why do we not renounce these privileges as the ill-gotten gains they appear to be?

If we allow ourselves to think this far, most of us do not tolerate the glare of these intractable, harsh questions very long and must avert our gaze. It feels too much like beating ourselves up. Eventually, we change the questions, accept patently false answers, or retreat behind one shield or another. Physician-anthropologist Paul Farmer's *Pathologies of Power*, [2] however, does not look away but resolutely examines the injustice in an "effort to reveal the ways in which

the most basic right—the right to survive—is trampled in an age of great affluence, and it argues that the matter should be considered the most pressing one of our times." (p 6) It is required reading.

Farmer is professor of medical anthropology at Harvard medical school, an infectious disease physician practicing in Boston's Brigham and Women's hospital, founder of the international Partners in Health, and an international consultant on TB and AIDS, but he spends a majority of his time caring for patients at a clinic in Cange, a small village on Haiti's Central Plateau. He is, therefore, uniquely positioned to explore the fundamental dichotomies of privilege and oppression, of power and powerlessness, of affluence and poverty that threaten our civilization. *Pathologies of Power* examines the nature of the structural violence that oppresses the world's majority and the role of government, academia, and the media in rendering that structural violence largely invisible. Farmer exposes the excuses of "limited resources" and "cost-effectiveness" and challenges head-on a theology of the free market that keeps us from even asking the relevant questions. Our failure to prevent preventable disease and our unwillingness to treat treatable disease, he suggests, are human rights abuses of the highest order. He indicts medical ethics' refusal to confront disparities in access to health care as tantamount to erasing the lives of countless people.

But why should we read it? I was aware of a strong temptation to turn away, and I'm sure I'm not alone. There is enough bad news in the press (and in our own lives) to dissuade us from accompanying Farmer in his explorations. Besides, the problems of structural violence and injustice seem insoluble and hopeless. But if we mean to survive as a civilization, we must not only look upon but ultimately also solve this self-reinforcing tangle of injustice in an ever-shrinking world. It threatens, in fact, to engulf us, impacting virtually every one of our possible apocalyptic futures: terrorism, nuclear proliferation, class war, immigration, environmental devastation, and others. We had better figure it out ... and soon! Fortunately, as painful as Farmer's description of his work in Haiti, his visits to Chiapas, Mexico, and his extensive consultations within the Russian prison system; as difficult as his analysis of the structural violence inherent in the systems that benefit us the affluent; his book is ultimately a work of hope, a clear-eyed look at what is wrong and what must change.

There are also deeply personal, spiritual reasons to expose ourselves to these issues. In sermons [3] preached years ago in Argentina, theologian Dorothee Sölle pointed out that when the privilege of some human beings depends upon particular social structures and those same structures are responsible for the suffering of others, then the people of privilege inevitably experience an "objective cynicism"—an alienation from God and their deeper selves, a separation from ultimate reality—that is not dependent upon subjective emotional or spiritual reactions but is "objective," built into the nature of being human. This alienation develops in people of privilege regardless of their intention and regardless of whether they directly cause

the oppression; merely benefiting from social structures that oppress others is enough.

Most of us will not be consciously aware of this alienation. It will express itself in anger toward the poor, fear of their poverty, isolationism, hoarding wealth, anxiety, anomie, or boredom. It is, however, a spiritual sickness, requiring healing. Sölle indicates that there is only one pathway to healing: solidarity with the poor, making their struggles our own. Paul Farmer not only refuses to look away from the injustice but also gives us some tools to maintain our gaze long enough to see through it to a *pragmatic* solidarity—an active solidarity—that can lead us out of our alienation. Paradoxically, then, the devastating, often painful critique within *Pathologies of Power* offers healing for the soul.

Twenty years ago I came to the inner city of Washington to offer medical care to people who could not afford to buy into the health care system. I practiced in a small neighborhood clinic that also received homeless men, women, and families from around the city; a group of us began and lived in Christ House, a 34-bed medical recovery shelter for homeless men; and we started Joseph's House, an 11-bed home and community for homeless men with AIDS where our family lived for three years. My experiences resonate deeply with Farmer's. The same systemic forces that claim the lives of Haitian peasants, campesinos in Chiapas, or prisoners in the Russian penal system also cause the suffering and death of people in inner city Washington DC.

The front page of this morning's *Washington Post*, for instance, highlights a continuing phenomenon of our city's poorer neighborhoods: random shootings. Utterly innocent people are killed by stray bullets intended for someone else. Simply to live in those neighborhoods, unable to move out because it's too expensive, subjects one to the risk of being maimed or killed, perhaps while sitting in one's own living room or on one's porch, by bullets intended for someone else. While we usually won't think of it this way, it is the structures of our society that kill those people sitting on their porch. Poverty in Washington DC—as in Haiti, Chiapas, or the Russian prison system—is a life-threatening condition. Poverty, the World Health Organization has recognized, is the world's greatest killer. (p 50)

Structural Violence

Acéphie Joseph was twenty-six when she died of AIDS in Haiti. She acquired the disease in a brief sexual relationship with a soldier when she was nineteen. She couldn't afford

medications or treatment for her disease and left an infant daughter, also infected. Shortly after she died, her father hanged himself. From one point of view, Acéphie died because of "fate" and poor personal choices.

Farmer suggests, however, that any analysis of Acéphie Joseph's story must be historically deep and geographically broad. One beginning point might be 1956 when Acéphie's family was forced out of their ancestral home and farmland in a fertile valley because the regime, in cooperation with international aid groups, built a dam that flooded the valley. Uncompensated for their loss, the Josephs were forced onto barren land and into penury. At age 19—about the time for her to bring in income for the family—Acéphie was courted by a soldier. Although her family knew the soldier was already married, he was one of the few men in the area with a steady income. Acéphie felt she had no other choice, no other chance to rise out of poverty. The relationship was brief because the soldier became ill shortly thereafter and died. Acéphie hadn't known he was HIV-positive, but she was already infected. There was no effective medical treatment during the late 1980s, but she wouldn't have been able to afford it anyway.

Or the story could begin in 1804, when Haiti was established as the world's first black republic and the United States boycotted it for fifty years and then supported various military dictators who over the years left the country impoverished. Or the story could begin in Africa when Acéphie's ancestors were rounded up and sold into slavery. We will not understand the death of Acéphie Joseph without understanding the wider context, including the active involvement of the United States and other Northern nations in impoverishing her country over two centuries.

A significant difference between blaming only fate and/or the poor personal choices of the victim, on the one hand, and understanding the geographical and historical context, on the other, is that the second point of view usually involves us—the beneficiaries of the wider economic and political system—directly in Acéphie's death. From that point of view, the primary cause of her death is the "structural violence" of the system in which she lived. "The term [structural violence] is apt because such 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." (p 40) Understandably, given our position in the dominant system, we would prefer to ignore the constraints on Acéphie's agency and see the causes of her death in her own choices. We would rather focus on the decisions and culture of the victims of structural violence rather than on the action and ideologies of its unseen perpetrators. We would rather blame the poor for their suffering, so we do not see clearly.

Robert McAfee Brown has written that "the world that is satisfying to us is the same world that

is utterly devastating to them." (p 41) We benefit from the very same structures that bring violence to the victims. If we don't personally know the suffering of individual poor people, their suffering (when we even hear about it) is quickly submerged by the busyness and difficulties of our own lives. (It is understandable, yet nevertheless instructive, how frequently public figures challenge particular structures when people they love have been its victims. Sarah Brady—whose husband, Ronald Reagan's first press secretary, was wounded in an assassination attempt—has pursued a sustained public campaign against handguns for over twenty years. Nancy Reagan's advocacy for stem cell research after her husband's dementia also comes to mind.) More important, to do something about the suffering would require significant sacrifice on our part. The cognitive dissonance between, on the one hand, the overwhelming suffering of the poor and, on the other, our attachment to our own way of life, makes turning away and "not seeing" quite understandable human behavior. "It stands to reason that, as beneficiaries of growing inequality, we don't like to be reminded of misery and squalor and failure." (p 176)

Farmer suggests some other reasons for our difficulty in seeing the structural nature of the violence. First, the victims are usually far away (usually geographically and always experientially) and their affliction is lurid, so their suffering becomes "exotic" and difficult to identify with. Second, he writes, the overwhelming weight of the suffering crushes our vision; he quotes Rebecca Chopp: "Knowledge of suffering cannot be conveyed in pure facts and figures, reportings that objectify the suffering of countless persons. The horror of suffering is not only its immensity but the faces of the anonymous victims who have little voice, let alone rights, in history." (p 40-41) Third, he claims that the dynamics and distribution of suffering are still poorly understood because "one must embed individual biography in the larger matrix of culture, history, and political economy." (p 41) While the latter may be technically correct in examining the exact chain of causation in any specific case, the overall dynamics and distribution of suffering are, in fact, well understood and are well explained by the nature of the world's economic and political systems. Money and power flows from the poor and powerless to the wealthy and powerful, making the suffering that Farmer documents virtually inevitable.

While well documented by those who study the matter, Farmer is certainly correct that these relationships are usually hidden from the public eye. In the United States, for instance, the usual health and mortality statistics that are published every year and regularly quoted are not kept by social class but by "race," an increasingly obvious and illegitimate social construction. So, we know, for example, that the infant mortality for non-Hispanic blacks is 2.3 times greater than for whites and that the life expectancy of whites is  $5\frac{1}{2}$  years greater than for blacks, but there are no regular reports about infant mortality or life expectancy among the American poor, so we can continue to imagine that these horrendous realities have something to do with the genetics or "culture" of African Americans (which we couldn't do much about) rather than income distribution (which we could do something about). When specific studies are done, of course, mortality rates are strongly related to class, by whatever definition of class one chooses to use: education, income, occupation, etc. (p 45)

Another aspect of the fog that keeps structural violence hidden is that the oppression is frequently the result of complex interactions of many specific factors that differ from place-to-place. Study of Acéphie Joseph must, as Farmer argues, start with the abductions of Africans centuries ago for slave labor, examine the systematic oppression of the world's first black republic by the US and European governments, study the consistent support that the United States has given to oppressive dictatorships since 1900, and then look closely at the complex relationships between the US government and Haiti over the last generation, including support for the recent toppling of the democratically elected Aristide government. To some degree we must be familiar with all of this if we are to understand the particulars of Acéphie's suffering. These are not simple issues; vested interests often obscure them; the usual media don't report them. For many of us who have grown up in the educational system of the privileged, therefore, brief descriptions of the structural dimensions of the suffering seem unbelievable, almost paranoid, so we refuse to believe the brief accounts or take them seriously. When we are confronted with the more thorough explanation, however, there is the tendency to throw up our hands, bemoan the complexity, and move on to something else. Either way we fail to understand.

As Farmer points out, however, underlying this complexity is a series of simple first principles of justice. When we commit ourselves and our resources primarily to the poor and vulnerable, these complexities begin to arrange themselves in far more understandable patterns. The briefer descriptions begin to suffice because they fit into patterns that we have seen in greater depth elsewhere.

Multiple Drug-Resistant Tuberculosis in Russian Prisons

In order to help us understand the larger patterns of structural violence, Farmer explicates some of the complexity of an epidemic of Multiple Drug-Resistant TuBerculosis (MDRTB) inside the Russian prison system. Since the demise of the Soviet Union, the Russian criminal justice and prison system have been woefully underfunded. Detentions before trial of up to a year (illegal under Russian law) are common, and the entire system is desperately overcrowded. In those conditions, of course, tuberculosis (TB) thrives, especially given the rising incidence of AIDS. The intermediate solution has been the establishment of approximately fifty penal colonies specifically for prisoners with TB. Because of minimal budgets, however, there is virtually no money for medications. Farmer visited a TB colony of 909 prisoners with an annual medication budget of just over \$2,000.

TB treatment is complex. It must include multiple (usually at least three) drugs given concurrently and consistently, and it must be prolonged (at least nine months and sometimes longer). Drug resistant stains of TB are common. If resistance develops to one drug and is not detected, it becomes increasingly likely that resistance to the second and third drugs will develop as well. When patients do not respond quickly to treatment, therefore, cultures must be taken and the bacilli tested for resistance to the particular drugs being used. Once the nature of the drug resistance is known, the ineffective drugs are dropped and much more expensive "second-line" drugs must be added to the regimen, taking care not to develop resistance in these second-line drugs. Once resistant strains do develop in one prisoner, of course, others who contract the disease from that prisoner contract the drug-resistant variety and begin from there.

TB treatment in the Russian penal system is glaringly inadequate primarily because the Russian economy has collapsed and little money has been provided to combat the epidemic. Most importantly, the prisons are overcrowded and poorly ventilated, leading inevitably to the spread of the disease. There is no money for MDRTB testing, so all prisoners are treated with the relatively cheap combination of the three primary drugs. Interruptions in the supply of one drug or another are common, which means that prisoners sometimes receive only two or even just one of the drugs, perfect conditions for development of drug resistance. Treatment is sometimes interrupted completely, and this off-again-on-again treatment is another incubator for drug resistance. Even when prisoners do not respond to the treatment (and therefore the diagnosis of MDRTB is highly likely), there is little money for testing and even less for the more expensive (and often just unavailable) second-line drugs. Since up to half of the prisoners in the Russian prison system with active TB has MDRTB, many of the new patients acquiring the disease contract the resistant variety.

The exact dimensions of this epidemic of MDRTB are unknown. Russian officials estimate that 10% of Russian prisoners (or 110,000) have TB. Since testing is not done, the prevalence of MDRTB is unknown, but estimates vary from 20% to 50% of the TB population. Even the most conservative figures, therefore, indicate 22,000 cases of MDRTB in the Russian prisons at any given time. This is by far the greatest known outbreak of MDRTB in the world, and current treatment practices will only insure its escalation.

Since treatment with the more expensive second-line drugs is rarely available, prisoners either die from the MDRTB while in prison or are discharged into the general population, which has caused a dramatic, three-fold rise in TB and in MDRTB in Russia. The outbreak, therefore, is not confined to the Russian prisons ... nor to geographic Russia, as increasing international travel spreads the disease widely. While starting among the poor, therefore, this epidemic threatens all of us.

What should be done? Medically, the answer is obvious. Decrease the crowding in prisons and increase the ventilation. Test all prisoners for TB and all diagnosed cases for MDRTB. Quarantine all patients with active TB in specially ventilated isolation units for several weeks until they can be rendered non-infectious with adequate treatment and continue following all patients until they are free of the disease (nine months or more). Even with adequate resources, this is not an easy task since many TB drugs have annoying and/or serious side effects that must be continually monitored. Patients find it difficult to continue treatment after they begin feeling well, so they must be continually monitored. But Farmer's own work in the slums of Lima, Peru, a situation even more difficult than Russian prisons, has demonstrated that it is *possible* to treat patients under severe conditions.

The stumbling block always, of course, is resources. A New York outbreak of 1,279 cases of MDRTB from 1991 – 94, of which 80% were traced to prisons and homeless shelters, is estimated to have cost \$1 billion in new and renovated facilities, personnel, medical care, and medications. With an outbreak somewhere between twenty and fifty times that size, "the Russian MDRTB is already so widespread that no single country, and certainly not one in the midst of economic turmoil, could ever hope to assume complete financial and technical responsibility for its control." (p 120) Russian prison doctors openly acknowledge the problem and are aware they are not offering proper treatment although, according to Farmer's expert assessment, they would be capable of doing so if resources were available to them. Russian prison officials also acknowledge the problem and its utmost seriousness yet, in post-Soviet Russia, they have no resources pass on.

A prison sentence in Russia has become for many a death sentence, even if the person detained is eventually determined not guilty. The injustice is glaring.

What are the primary causes of this situation that not only flaunts any idea of justice but eventually also threatens the rest of the world? Why hasn't anything been done? Although medical resources were also strained during the Soviet era, prison officials contend that they then had the requisite resources, were able to do the needed testing, and received the needed medications. The MDRTB outbreak is a phenomenon of post-Soviet Russia, the privatization of resources, and the battering of the Russian economy at the hands of unfettered free-market capitalism. Privatization and "health care reform" have led to a massive reduction in public health care expenditures, and of course the few private, for-profit medical resources available will not find much profit in treating prisoners or even their families.

The most immediate problem for medical officers in the prison system is the cost of the medications, especially the second-line drugs necessary to treat MDRTB. Since most of them have been off patent for years, they should be relatively inexpensive, but pharmaceutical companies have nevertheless kept the cost high. Medications for an entire course of treatment with the much less expensive first-line drugs can be purchased for less than \$100, but the less commonly used second-line drugs for MDRTB, requiring a much longer treatment period, can cost tens of thousands of dollars per treatment regimen.

What has been the response of international health organizations and experts? According to Farmer, the primary response has been to blame either the "antiquated" Russian health care system, the Russian doctors for not following accepted protocols, or the prisoners themselves for noncompliance. The experts, he says, continue to insist that the proper treatment for tuberculosis in poor countries like Russia is "Directly Observed Therapy, Short course" or DOTS. Under ordinary circumstances, DOTS is the exactly appropriate treatment. The three cheap, first-line drugs are given under direct observation by a member of the health care team to facilitate patient compliance (taking multiple medications, some with side effects, every day for nine months is not easy). "Short course" is the usual nine months. But circumstances in the Russian prisons are not ordinary, and DOTS makes no sense in cases of MDRTB since the bacilli are resistant to most if not all of the first-line drugs. Russian prison health officials that Farmer has interviewed understand the problems and are quite competent to treat the disease. They follow DOTS scrupulously as the international experts recommend. But, as could be predicted, thousands of inmates fail the therapy. It shouldn't be expected to work!

But the actual nature of this specific structural violence remains obscure, apparently, even to the experts.

International expert opinion has tended to blame poor treatment outcomes on the hapless TB services, both prison and civilian, or on a lingering "Soviet culture," rather than on the social and economic conditions that are at the heart of both the epidemic of imprisonment and the epidemic of tuberculosis. Worse still, many international experts continue to insist that the prescription for Russia's runaway TB epidemic must include *only* the wise use of first-line drugs—this at a time when fully half of all patients with active disease are sick with strains resistant to isoniazid or streptomycin [two first-line drugs]." (p 120) (italics mine)

Or it's the prisoners themselves who must be noncompliant. Such views would seem to stem from ignorance of the treatment now necessary for MDRTB, but these are the international experts themselves. Yes, it would be theoretically possible that the outbreak resulted from an antiquated Soviet culture, poorly trained physicians, or patient non-compliance, but Farmer (an

internationally recognized expert himself) takes pains to demonstrate that in his experience the doctors are competent and seem to have used DOTS consistently and that the prisoners themselves are eager to be treated and capable of complying. So what's the problem with the other experts?

Pushing further, Farmer discovers that many international experts don't believe it is "possible" to treat MDRTB in such circumstances. To rebut that Farmer describes a successful trial by his Partners in Health in the slums of Lima, Peru, in which there was an outbreak of MDRTB. "Public health officials in Peru and the United States, as well as from the World Health Organization, cautioned that we could not expect good results." (p 122) But, although it was certainly expensive, most of the fifty patients in the trial responded to treatment and at the end of two years 80% were free of persistent disease, demonstrating that it is possible to treat MDRTB in such difficult circumstances.

The real—though unarticulated—reason for insisting on DOTS in the Russian prison system, for declaring the patients "untreatable," is that confronting the actual problem would "cost too much." And, of course, it's true that it would cost too much in terms of resources currently allocated to the problem. But such narrow judgments miss the larger picture, for instance, the \$130 billion capital flight out of Russia between 1993 and 2000—after the sale, encouraged by Western economic advisers, of the majority of public assets at bargain prices. We live in a time when resources are less limited than ever before in history. When the wealth of any one of several individuals could provide medications for every TB victim (including those with MDRTB) in Russia, it is difficult to say that there isn't enough money to treat thousands of Russian prisoners who have been given a death sentence during their detentions. The real problem is not "limited resources" but unjust distribution of wealth and the powerlessness of national governments to control corporate profit or the upward flow of money and resources from the powerless to the powerful. In today's world, "limited resources" is nothing more than a euphemism for injustice.

According to Farmer, international health experts, actually, don't talk as much about "limited resources" as about "cost effectiveness." The reason given for treating all Russian tuberculosis prisoners with the usual combination of first-line drugs (when an estimated 20 – 50% of them have MDRTB) is that it's not "cost effective" to use the more expensive second-line drugs. What they mean, of course, is that their budgets are limited and it makes more sense to treat everyone with the cheaper regimens than a limited number of MDRTB patients with the more expensive regimens. Appropriate treatment for all prisoners with MDRTB would not be "cost effective." And it's true: if one looks narrowly at the budgets of international health organizations, triage is necessary and specialists must make narrow judgments of *relative* cost effectiveness. Translated, of course, "cost effective" means that the lives of thousands of prisoners are not worth saving.

Is it fair, however, to blame the international health experts and organizations with limited budgets for the economic structuring of our society? Of course not. But it *is* fair to insist that they not cover up the reality of the suffering by continuing to publicly insist that DOTS is the recommended treatment for everyone in the Russian prison system. It is fair to insist that they stop declaring the patients "untreatable." It is fair to insist that they provide a translation for their explanation that it's not "cost effective" to treat people dying to MDRTB, that they remind the public that the question is, in actuality, justice. It is fair to blame the experts for exculpating an economic and political system that refuses to treat treatable patients and sentences them to death. Their explanations cover up a dirty reality of the unfettered free-market economic order. It's the same economic and political system that so benefits the experts (and us) that refuses to make adequate TB treatment available to tens of thousands of Russian prisoners. (This would be merely immoral and sinful if we could somehow confine the epidemic to the Russian prisons or, even, to Russia itself. But these false explanations become just plain stupid when one considers that MDRTB will not confine itself to Russian prisons or to Russia itself but will spread around the world.)

Whether intentionally or not, the response of the international health community to the Russian prison MDRTB epidemic refuses to challenge the morality and adequacy of an unfettered, free-market capitalism. By looking narrowly at their own budgets, their judgment of "cost infectiveness" illustrates the ideologically based, Let's-Not-Think-Too-Deeply-About-It typical of the champions of The Market. The ideology is that we will have the best of possible worlds if we just remove the governmental restraints and allow The Market to function with utter freedom. Sure, drug companies will charge what the market will bear for their second-line anti-MDRTB drugs; yes, the Russian government must cut its governmental services to the bone in order to qualify for international loans; true, capital generated by the fire sale of Russian public assets will flee the country; no, you couldn't expect private services to treat prisoners since they can't pay; nevertheless, the free market is the best of all possible worlds and will ultimately bring us all to prosperity. Besides, (continues the ideologue) we know communism doesn't work, so what other economic system is there? So, rather than indicting the injustice of the economic and political order, the international health community supplies cover stories that keep the injustice of (and our responsibility for) the tragedy hidden from the public. Medically nonsensical sound bites conceal structural violence.

Some justify opposition to the aggressive treatment of MDRTB in developing countries as public health *realpolitik*, but careful systemic analysis casts doubt on such notions. Although our failure to effectively confront tuberculosis is obvious, the hypothesis that we lack sufficient means to cure all tuberculosis cases, everywhere and regardless of susceptibility patters, is not supported by data. There is plenty of money—even in many poor countries. The degree of accumulated wealth in the world today is altogether unprecedented, but this accumulation has occurred in tandem with growing inequality. (p 172)

## Preferential option for the poor

Unfettered free-market capitalism is best defended philosophically by a version of utilitarianism, popularly defined as "the greatest good for the greatest number." To garner support for capitalism, however, the definition needs to be stretched a bit to "the greatest good for the greatest number—eventually," for then it's possible to justify the suffering of the poor and excluded on the basis that the system will someday get us to the point where the unfettered free market brings about the greatest good for the greatest number. Such a faith in unfettered capitalism, however, is ideological since there is so little evidence for it. Since the unfettering of the free market a generation ago, inequality in the United States and around the world has increased substantially. Worse, only the most rigid ideologues believe there is a free-market solution to the most pressing problems of our times. How does one prevent pollution when the most cost-effective ways of producing many goods involve gross pollution? How does one stop global warming when it is in the best interest of the coal and oil industries to sell their products as widely as possible? How does one preserve resources for future generations? Where does the money come from to support people who cannot support themselves, who don't do well in a competitive market? Do we really believe in a social Darwinism that simply rejects those who can't keep up?

But even if the free market were able to solve these problems and get us to the greatest good for the greatest number, popular utilitarianism still justifies the suffering of some for the benefit of others. What number of MDRTB prisoners are we willing to let die rather than mount an extensive, expensive international campaign to treat them? What is the acceptable number of the world's children dying every day from preventable diseases? How many ghetto residents can we educate inadequately, subject to disease, and surround with violence before it becomes unacceptable? There is a "cost-benefit analysis" inherent in utilitarianism that most of us would find morally repugnant if face-to-face with the losers.

Farmer suggests an alternative perspective for social analysis: "How is [the matter at hand] relevant to the suffering of the poor and to the relief of that suffering?" (p 138) He looks for inspiration to liberation theology's "preferential option for the poor." Theologically based, of course, on Biblical teachings—both Hebrew Bible and New Testament—liberation theology arose in South American "base communities" in the experience of poor and oppressed people reading the Gospel texts. They discovered in the texts a perspective on power from the point of view of the oppressed; they discovered that Judeo-Christian teachings, at least, judge the world from the point of view of the world in other words, gives one a more coherent moral picture of the world than other perspectives. Farmer writes:

Truth—and liberation theology, in contrast to much postmodern attitudinizing, believes in historical accuracy—is to be found in the perspective of those who suffer unjust privation. Cornel West argues that "the condition of truth is to allow the suffering to speak. It doesn't mean that those who suffer have a monopoly on truth, but it means that the condition of truth to merge must be in tune with those who are undergoing social misery—socially induced forms of suffering." (p 153)

Although Farmer doesn't mention it, the work of twentieth-century secular philosopher John Rawls suggests that precisely this preferential option for the poor is in fact closest to true justice. Briefly, Rawls believes that the only fair way to devise a just social order would be for those devising it to be unaware of their status in the society. To consider justice, Rawls suggests we step behind a hypothetical "veil of ignorance" rendering us temporarily unaware of whether we are, in fact, rich or poor, more intelligent or less, industrious or undisciplined, able-bodied or invalid, black or white, oppressed or free, etc. Rawls then shows that behind that veil of ignorance rational people would choose to create societies with two features: first, equal political rights for all and, second, a preferential option for the poor and oppressed (although he doesn't use that language). We would choose the preferential option for the poor because we would want to avoid abject misery that would come our way if we turned out to be among the oppressed. We would be willing (behind a veil of ignorance) to give up a marginal degree of privileges (if we turned out to be among the privileged group) in order to avoid the chance of misery. Behind a veil of ignorance, people would understand that it was in their best interest to create structures that would take marginal privileges away from the privileged in order to secure basic well being for everyone.

The problem, of course, is that those who set the rules for society's structures know precisely to which class they belong, so they don't see the structural violence the system creates, and they don't experience the misery of the losers. But if even those of us who are privileged have the experience of living and working with the oppressed and understanding the structural violence to which they are subjected, our perspective changes, and the preferential option for the poor becomes a moral imperative.

One belief that keeps many of us from seeing the injustice to which the poor are subjected is that most poverty is a result of the individual failings of the poor, that everyone can "make it" if they just work hard enough. It's easy to look superficially at groups of poor people and blame their personal choices. But, although there are exceptions, few who study the situation carefully or who live or work for any length of time with the poor maintain that belief. It's not that individual poor people don't have failings: we all do. It is that in most cases structures beyond the control of individuals create the poverty. In the vast majority of cases in which individual

choices seem to be the cause of the oppression, closer examination will reveal, as in Acéphie's case, that (sometimes hidden) oppressive structures are largely responsible for the choices, too.

In inner city Washington, for instance, single parenthood and joblessness are clear proximate causes of poverty. But why are so many ghetto women single parents? "Marriageable" men (that is men who have steady jobs that can support a family) are few. Desperation and hopelessness result in adolescent parenthood. The pressures of inner-city life cause a high rate of divorce. Spousal abuse is more common than previously thought. Throughout the society single parenthood is becoming more common. And so on. And why are so many ghetto residents jobless? There are few jobs within or near the ghetto for less skilled people that pay a living wage. Nearly a majority of men have prison records that make employment even more difficult (and a study of the criminal justice system reveals vast inequities). Studies show that African Americans are the "last hired and first fired." Poor education means limited job horizons. And so on. (Critics will, of course, point to some of the above causes—spouse abuse or criminal records or dropping out of school—as personal choices, but closer looks reveal each of them to be also largely determined by social structures.)

And this is one of Farmer's important contributions. As he looks carefully at AIDS in Haiti, poverty in Chiapas, or the MDRTB epidemic in Russia, the reader begins to see the vast social forces arrayed against people who, on first look, seem to have brought their poverty upon themselves. He brings us into those communities and shows us the structural violence. He also makes us uncomfortable by showing us our responsibility and the way that many evade it.

Does everyone have the *right* to the absolute necessities of life? Certainly the 1948 framers of the UN Universal Declaration of Human Rights thought so. Articles 25 and 26 declare that everyone has a right to food, clothing, housing, medical care and education. In practice, of course, human rights have been narrowed to civil and political rights. A dictionary definition suggests that human rights are limited to "the right to life and liberty, freedom of thought and expression, and equality before the law." Jeane Kirkpatrick, Ronald Reagan's ambassador to the United Nation went so far as to term the Declaration "a letter to Santa Claus" largely because of the inclusion of economic and social rights. Even the human rights community has largely satisfied itself with raising the alarm about political freedoms and torture.

If we understand, however, that structural violence is responsible for much of poverty, for the majority of premature deaths, for inestimable suffering, we see that structural violence threatens the right to life and liberty, even equality before the law. Aside from intention, what is the difference between torture and a slow death from untreated tuberculosis or AIDS? "The

absence of social and economic power empties political rights of their substance," writes Farmer. (p 16-17) We cannot protect the civil and political rights of people if their basic rights to food, housing, clothing, education, and health care are not met. Social and economic rights, including health care, it seems clear, must be considered human rights.

When we regard the perpetrators of these crimes [upon the poor] from any comfortable reserve, it is important to recall that with our comfort comes a loss of innocence, since we profit from a social and economic order that promises a body count. That is, surely there are direct and causal relationships between a protected minority enjoying great ease and those billions who go without the bare necessities of food, shelter, potable water, and medical services? Pathologies of power are also symptoms of surfeit—of the excess that I like as much as the next guy. (p 255)

Political and economic structures are responsible for much of the world's poverty and the consequent loss of human rights. But how does that implicate us who are more affluent? The problem, of course, is that our affluence is dependent upon those same structures that oppress others. A fog of misunderstanding surrounds those structures—generated mostly by those same political and economic structures (especially the media)—that makes it easy for us to avoid recognizing the truth and maintaining our illusions of innocence. Farmer looks at direct US government support to repressive governments, the neo-liberal organization of the world economy, an unfettered free-market economy, and the simple facts of our extreme affluence and their extreme poverty and the increasing levels of inequality over the last decades to suggest that our affluence is, in fact, related to their poverty.

Direct US government support to repressive governments is a primary reason for much suffering around the world. The United States has been directly or indirectly involved in undermining democratic government in Haiti for two centuries, actively supporting, for instance, the Duvalier regimes for many years. The United States government's support of right-wing, murderous dictatorships in Guatemala and El Salvador and support for the Contras against Nicaragua during the 1980s is well known. Similar stories can be told from all over the globe: the CIA sponsored coup against the Iranian democracy in 1953, backing the Apartheid government in South Africa, long-term military and political assistance for the Saudi regime, political and military support of Israel against the Palestinians, to name a few. Our government, in other words, has been directly involved in the oppression of poor people around the world. Since we have benefited from our country's military and economic power, the responsibility to repair the damage is ours.

Beyond the direct US support for oppressive governments around the world, there is the fact

of the neoliberal organization of the international economy that has dominated for the last several generations through the World Bank and International Monetary Fund and more recently through trade agreements such as the North American Free Trade Association (NAFTA) and the World Trade Organization (WTO). While the details of how those international organizations and agreements oppress the poor are too complex to describe in this essay, they include demands that poor countries reduce their social budgets (for instance, draconian cuts in spending on education or health care); bans on government support of exported goods (with the morally inexplicable exceptions of US and British support for their own agriculture that ends up severely penalizing Third World countries who are prohibited from doing the same thing); the weakening of unions and other protections for workers; rules that allow instantaneous, electronic flows of speculative capital in and out of countries (often destabilizing smaller economies); agreements permitting transnational corporations to sue countries for impeding their pursuit of profit; and so on. Since we benefit from these neoliberal economic agreements, we have a responsibility to repair the damage.

Underneath the harm done by neoliberal economic agreements, there is the unfettered free market itself that has allowed large multinational corporations to dominate the economies of poor countries. According to Adam Smith, a founding father of capitalism, the "invisible hand" that is supposed to guide free-market capitalism in creating a just system makes a basic assumption that monopolies will be controlled and strict limits will be placed on foreign trade to protect domestic producers. Modern international capitalism has abandoned both of those supports, so the poor of the world are decimated as, for instance, farmland that once supported peasants becomes a banana or coffee plantation for export and most of the peasants must join the legions of unemployed in the cities... in order that we gain cheap bananas and coffee. Since we benefit directly from an unfettered free market, we are responsible to repair the damage.

If none of those arguments convinces us, there is still the raw fact of our surfeit and their misery. To put it most starkly, a few of the dollars that I spend on things that I don't really need can literally save the lives of particular human beings. Within most ethical systems, that makes me responsible to use my income wisely and dismantle structures of violence.

The Media

There is another powerful reason why it is difficult for us who are affluent to make these connections. Our popular media consistently obscure reality so that we cannot see clearly. Farmer contrasts, for instance, media treatment of two government quarantines on the island of Cuba. The first is the US military base at Guantánamo Bay where in the early 1990s a few

hundred HIV-positive Haitians fleeing the island by boat were quarantined for up to two years. This was after the US-supported military coup against the government of the popularly elected Jean Baptiste Aristide. Many Haitians who had resisted the coup fled for their lives. Of those caught by US authorities the vast majority was forcibly repatriated, (illegal under international law). After intervention by human rights organizations, a compromise was reached in which some Haitians were sent to a detention facility at Guantánamo. HIV-positive refugees were quarantined in conditions that are remarkably similar to those experienced recently in the prison camps in Iraq (and, most likely again in Guantánamo). Refugees were denied legal counsel or hearings, and press coverage was prevented. A federal judge eventually described some of the conditions:

They live in camps surrounded by razor barbed wire. They tie plastic garbage bags to the sides of the building to keep the rain out. They sleep on cots and hang sheets to create some semblance or privacy. They are guarded by the military and are not permitted to leave the camp, except under military escort. The Haitian detainees have been subjected to pre-dawn military sweeps as they sleep by as many as 400 soldiers dressed in full riot gear. They are confined like prisoners and are subject to detention in the brig without hearing for camp rule infraction. (p 61)

Yolande describes her detention even more graphically:

Camp 7 was a little space on a hill. They put up a tent, but when it rained you got wet. The sun came up and we were baking in it. We slept on the rocks; there were no beds. And each little space was separated by barbed wire. We couldn't even turn around without being injured by the barbed wire.

She also describes *forced* Depo-Provera injections (for contraception) by military medics, a clear violation of medical ethics and, again, international law.

These were not criminals, but political refugees fleeing for their lives.

The second place that Farmer visits in Cuba is a sanatorium run by the Cuban government where, for a time, HIV patients were forcibly quarantined. (The forcible quarantine was lifted in 1993 although government surveillance of identified AIDS patients continued.) The sanatorium

is "a suburban community of several acres dotted with modern, one- and two-story apartments duplexes surrounded by lush vegetation, palm trees and small gardens." (p 53) Farmer interviews the medical director and several of the residents there and is impressed by the medical care given the HIV-positive patients and by their living conditions. Acknowledging the involuntary nature of some of the restrictions, such as mandatory testing, Farmer notes that Cuba's policies have resulted in the lowest incidence of AIDS in the Western hemisphere.

Farmer then examines US press accounts of the two places. The US controlled base at Guantánamo is described in a *New York Times* article headline as an "Oasis to Haitians," and other stories in the mainstream US media portrayed it as "a haven for refugees." A *New England Journal of Medicine* 

article states, "That the military physicians worked hard to treat the Haitians at the camp was not in dispute" (p 62) (an opinion not shared by the HIV-infected Yolande Jean) and goes on to blame "cultural differences" for some of the difficulties at Guantánamo.

The sanatorium run by the Cuban government, however, is described by a *Chicago Tribune* headline as a "prison" and a

Los Angeles Times

headline calls it "frightening." US press criticism of Cuba's decision to quarantine HIV-positive patients was common. Farmer sums up:

[I]n 1991, on a military base beyond the rule of law, the world's only remaining superpower simultaneously engaged in and denied officially sanctioned violations of the rights of HIV-positive Haitian refugees. The same newspaper that termed this US military base an "oasis" for Haitians readily printed highly critical assessments of Cuba's sanatoriums. ... The point is that understanding the complexities of AIDS and quarantine requires wading through a swamp of ideology. (p 74-75)

I regularly experience such biases in press reporting of conditions in the inner city. My favorite is a long, front-page article from the *Washington Post* during the height of the debate on Welfare Reform. The title of the article is "Welfare Clients Already Work, Off the Books"

and the slant of the article is that most welfare recipients are guilty of welfare fraud because they're bringing in income that they're not reporting (because they would lose welfare benefits if they reported it). The article relies heavily on a just published report by Kathryn Edin and Laura Lein that indicates that virtually 100% of the welfare mothers they interviewed were bringing in extra income above their welfare checks. The point of Edin and Lein's report, however, was not welfare fraud but that welfare payments were so low that no one could possibly live on them;

welfare mothers, therefore, had virtually no choice except to bring in extra income in order to support themselves and their families. Although this point was eventually acknowledged buried deep inside the

Post

article, most readers would see the emphasis on welfare fraud. The journalists had taken a report on the

necessity

of welfare mothers bringing in additional income and turned it into an article on their welfare fraud!

My point is not that the media is necessarily intentionally deceiving us, although in some cases that is also true. The point is that journalists and other media authors, editors and publishers come to their work shaped by the same biases that shape the rest of American culture. They are primarily affluent people living in a country that has provided them that affluence. Without great effort to shed the biased class and cultural lenses they have grown, they will *see* the world through those lenses. Intentionally or not, however, reports on the conditions of the poor will be ignored or seriously distorted, and the injustice perpetuated.

## An Unfettered Free Market

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 of these 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. (p 175)

An extended analysis of the role of the unfettered free market in structural violence around the world is, obviously, beyond the scope of this paper. Nevertheless, we must acknowledge some of the basic questions of such a critique.

- There is the "problem of the commons." How do we protect our environment from ravage or our natural resources from depletion in a system in which profits are the single motive?
- How do we keep monopolies from developing? How do we keep the corporations from becoming so large and powerful that they can keep unions at bay dictate the wages rather than bargain as equals with their employees (Wal-Mart being a most obvious contemporary example)?
  - How do we provide for those who cannot compete?

- How do we provide adequate health care and education for everyone under a system that distributes even the necessities according to who has the most money?
- Do we allow manufacturers of essential goods to set prices at whatever level the market will bear, as in the case of pharmaceutical companies and their life-saving drugs that the poor cannot afford?

"As a physician who has worked for much of my adult life among the poor of Haiti and the United States," writes Farmer, "I know that the laws of supply and demand will rarely sever the interest of my patients." (p 5) We

must acknowledge that the commodification of medicine invariably punishes the vulnerable. A truly committed quest for high-quality care for the destitute sick starts from the perspective that health is a fundamental human right. In contrast, commodified medicine invariably begins with the notion that health is a desirable outcome to be attained through the purchase of the right goods and services. Socialized medicine in industrialized countries is no doubt a step up from a situation in which market forces determine who has access to care. But a perspective based in liberation theology highlights the fundamental weakness of this and other strategies of the affluent: if the governments of Scandinavian countries and that of France, for example, then spend a great deal of effort barring noncitizens from access to health care services, they will find few critics within their borders. (Indeed, the social democracies share a mania for border control.) But we will critique them, and bitterly, because access to the fruits of science and medicine should not be determined by passports, but rather by need. The "health care for all" movement in the United States will never be morally robust until it truly means "all." (p 152-3)

What Shall We Do?

So ... it seems that those of us committed to justice for the poor are up against a brick wall. How do we begin to challenge structural violence if the power of capitalism, the powers of the corporations, the power of the media, the powers of governments and, it seems, most other human sources of power are arrayed on the other side? Once we have made the analysis, what's the next step? What do we do? What do I do?

The health care community has a unique position of power and privilege from which to address these complex issues of structural violence. In the last generation our community has taken on other questions of violence—for instance, gun violence, and auto safety—and impacted public policy significantly. We have the potential to reframe the debate about issues

of structural violence, especially as they impact health and mortality. We will not do so, however, by accepting the limited horizons of traditional politics or economics, by accepting the concepts of "cost effectiveness" or limited funding when they lead to death and suffering. Rather, we must raise our standards. Only when the destitute get the best medical care will we have fulfilled the requirements of health care justice from the point of view of the poor. We have the capacity to lead a movement to make health care a generally established human right.

As a first step in dealing with structural violence, Farmer suggests that health and healing become the "symbolic core" of the agenda, tapping into the universal concern for the sick. But in order for our expressed solidarity to become "pragmatic," it is the *provision* of health care that must become central to our agenda, not a "cost effective" care, not "sustainable" care but a provision of care for the poor that is at least equal to that given the affluent. It will, of course, be no short struggle. Farmer again: "In arguing that health care is a human right, one signs on to a lifetime of work dedicated to erasing double standards for rich and poor." (p 201)

One initiative must be in the area of research. While the general patterns disease, illness and death resulting from poverty are clear, the blinders of the affluent keep us from recognizing those general patterns. Needed is further research elucidating the particular mechanisms that translate injustice into poor health. As mentioned above, we in the United States don't even have good statistics showing infant mortality or life expectancy differences between socioeconomic classes since most of our data is tabulated by race, an imperfect marker for poverty. Why do the poor have more hypertension, more diabetes, more obesity? We don't really know the details, and we have not begun to relate our research to society's injustice. (As a physician I was startled to read some of Farmer's research papers because he does

with some passion include the injustice in the chain of causation. [See, for example, <a href="http://www.pih.org/library/essays/IntroducingARVs/plenarytalk.pdf">http://www.pih.org/library/essays/IntroducingARVs/plenarytalk.pdf</a>

.] Rarely are such connections made in our research reporting.)

Medical ethics is another area that we must greatly enlarge in scope. What is now defined in medical, nursing, and other health professions schools as an ethical issue? Does it include the deprivation of the vast segments of the human population from adequate medical care? When was the last time anyone on a hospital ethics consultation team spoke to the poverty of a patient hospitalized with a stroke after a lifetime of inadequate treatment of hypertension, pointing out that the doctors or hospital must change their practices? Do even our medical ethics boards operate out of the unacknowledged assumption that human beings are *not*, in fact, created equal? Do we ignore the glaring reality that this inequality is responsible for differences in health care, illness and death across groups of people? Has medical ethics become "yet another strategy for managing inequality"? (p 201)

All health professions students study medical ethics to some degree so medical ethics can become the contact point with the educational system for teaching about structural violence and the need for pragmatic solidarity. Curricula must aim to place students in face-to-face contact with the oppressed (in such environments as student-run clinics or internships in poor areas) but emphasize that the primary emphasis is on *learning* from the poor, not simply offering services.

Politically, we must agitate for increased resources for health and human rights. We are in an age when we continually urge the government to do more but then slash budgets. The voice of the medical community must agitate for restoration of budgets and then significant increases. The state cannot withdraw from its basic obligation of securing human rights, one of which is health care. We must exert our political pressure to that goal.

We should not underestimate the power of the health care community's voice in advocating for justice. Our patients and communities still trust us, and we can become sources of information to counter the propaganda of the media. We in health care must, to some significant degree, become activists, at least *speaking out* on issues of injustice, if we mean to retain the title of healers.

Farmer cautions us, however, about too much research and too much talk (not that most of us are in danger of overindulging quite yet). Ultimately our research and our advocacy must be based in the needs of the poor. When Farmer talks with his patients in Haiti, they don't speak very often about the need for research or advocacy. What they need is food, shelter, education and health care. There is the very real danger that as we abstract ourselves from the concrete life circumstances of the poor we will misunderstand and misdirect our activities. Because we who will do the research or advocacy work are (largely) not poor, we will too often follow our mistaken assumptions and prejudices about the poor. Accordingly, part of our task in health care is to engage the poor, to be in dialog, to come into relationship and stay in a position to hear their truth. We must begin to include the poor into our practices, in our deliberations, in our medical education (as *educators*, not just clinic patients); we must find ways to enter into face-to-face relationships with people who experience the structural violence of the society.

Every day, thousands of people die stupid deaths, utterly preventable deaths. We who accept the benefits of the economic, political and social structures that make such deaths possible have the responsibility to change that situation. It's a moral and spiritual imperative. We have largely abandoned the effort. Let us begin again.

[1] As Farmer emphasizes, this is not a misprint. See The World Bank's *World Development Report 1993*, table A.3 on p 200

- [2] Farmer, Paul, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, University of California Press, Berkeley CA, 2003.
  - [3] Sölle, Dorothee, Choosing Life
  - [4] Vobejda, Barbara and Havemann, Judith, "Welfare Clients Already Work, Off the Books," Washington Post, Nov 3, 1997, p A1