Listening for Prophetic Voices in Medicine

By PAUL FARMER

THE OLD TESTAMENT PROPHETS cannot have had a very easy time of it, and not because their primary work was as clairvoyants or seers. The prophetic voice was more often raised in protest against the social conditions endured by widows, orphans and the poor majority. These voices were raised in opposition to what may be termed structural violence—the poverty and inequality that bring opulent excess to a few and misery to many. Many prophets were regarded by their literate contemporaries as certifiably mad; few were heeded.

In many ways the prophets failed, for the inequities they deplored continue to run their course. A growing and globalizing market economy has not lifted, as promised, all boats. Instead, increasing wealth has lead to entrenched excess and squalor. We read in the newspapers of famine and strife, but also of the stunning success of luxury items. The Roaring Nineties are notable for waiting lists for $4,000 handbags and $44,000 watches; $75,000 cars sell like hotcakes. Inequality is very much the sign of our times.

The experiences of those who are sick and poor remind us that inequalities of access and outcome constitute the chief drama of modern medicine.

It is clear that modern biomedicine, like the global economy, is booming. Never before have the fruits of basic science been so readily translated into life-promoting technologies. But inequalities of access and outcome increasingly dominate the health care arena. In the United States, investor-owned health plans have rapidly transformed the way we confront illness. Although there is much talk of cost effectiveness or reform, the principal feature of these transformations has been the consolidation of a major industry with the same goal as other industries—to turn a profit. One of the cheerleaders for this new, soulless trend put it this way: "There is no longer a role for non-profit health plans in the new health care environment." Do we recognize, in this "new health care environment," today's prophetic voices? Unless we make our world a place free of structural violence, we cannot suppress these voices. We can only ignore them. The experiences of those

PAUL FARMER, M.D., is assistant professor at Harvard Medical School and the medical director of the Clinique Bon Sauveur in Cange, Haiti. This essay is based on an address given in Corpus Christi, Tex., on March 15 to the Catholic Health Association of America and the National Association of Catholic Chaplains.

who are sick and poor—sick, often enough, because they are poor—remind us that inequalities of access and outcome constitute the chief drama of modern medicine. In an increasingly interconnected world, inequalities are both local and global, as examples from my own practice will illustrate.

Brenda and the Excuses of Our Times.

Brenda, a native of Boston, has advanced AIDS. She doesn't know how she acquired H.I.V.—increasingly, people don't know—but she guesses it was from the father of her first child, because he had used heroin. Brenda herself never did. A mere 28 years old, she is already almost blind. She weighs 89 pounds and has great difficulty taking care of her children, even with help. Her goal, she once said, was to see her oldest child graduate from high school. In recent years, she has downgraded her aspirations. Since Andrew is now seven, she'd like to see him graduate from junior high school.

This year, however, Brenda allowed herself to hope. She had heard about the powerful new combination of drugs that seemed to revive even the near-dead; and she herself knew a woman with AIDS who, on these drugs, went from bedridden to buoyant—at least, that was Brenda's impression—in a matter of months.

At last, thought Brenda, who while taking other antiviral medications had suffered through side effects ranging from pancreatitis to unremitting nausea only to learn that these medications had little demonstrable effect on the course of her disease.

But there was a glitch. In the course of her previous, ineffective therapies, she had shown herself to be "noncompliant." This label made it difficult for her to participate in the clinical trials that are so often the only affordable source of these drugs. The New York Times recently reported that doctors are now rationing protease inhibitors, saving them for those deemed likely to comply.

There is no doubt that my colleagues do this with the best of intentions, but there are serious flaws in such strategies. First, research has shown that physicians are poor predictors of compliance with prescribed regimens. Second, those least likely to comply are usually those least able to comply. Willful noncompliance is what we term a "diagnosis of exclusion."

Third, rationing effective therapies can actually serve to deepen the gaps between the rich and the poor. If marginally effective treatments for H.I.V. disease are not available to the poor, then their health suffers only marginally. But if highly effective therapies—such as the recently developed antiviral cocktails—are unavailable to those living in poverty, then class-based inequalities of outcome worsen with time. Through such mechanisms, our failure to make sure that people like Brenda receive such medications is tantamount to "structural sin."

The excuses of our times are often ingenious. The Wall Street Journal ran a front-page story under the title "Precious Pills" about the protease inhibitors and responses to them. A subheading read, "Gotta Clean Up Your Act." But what, exactly, do I tell my patients, many of whom, like Brenda, are as likely to lack day planners as they are to lack day care? If I could acknowledge that their lives have been damaged by racism and, often enough, gender inequality, if only I could say this in an appropriate way, I would. If I could tell them that they deserved the best medical care I can deliver, I'd tell them that, too. There are many things I would like to tell them, but somehow I cannot bring myself to recommend that they "clean up their act."

Perhaps it's time that we clean up our own acts. When my colleagues and I published *Women, Poverty and AIDS,* we berated fellow physicians and academics for our collective failure to appreciate how gender inequality and poverty were putting millions of women at risk for H.I.V. infection. Although we've received many supportive letters in response to our book, some scholars resented having their work criticized for not being mindful enough of the plight of poor women. But the entire point of the volume was to analyze massive failure—the public-health failure to prevent AIDS from becoming, in a single generation, the leading cause of death of young women living in poverty; the failure on the part of researchers to make clear the mechanisms by which poverty and gender inequality create situations of risk for poor women; the failure of physicians to insist that H.I.V. care be made available to poor women; the failure to care enough about a catastrophe that increasingly affects largely the poor. Indeed, by what measure is the AIDS pandemic among women not a failure?

Brenda eventually got her medications, and she's doing better. If you'll permit a bit of sarcasm, it is almost as if she had a treatable infectious disease.

Sanoît and the Disposable Millions.

I spend half my time seeing patients in the Clinique Bon Sauveur in Cange, Haiti. The facility serves largely the landless poor and the peasants of the central plateau's arid highlands. Sanoît showed up in the clinic looking like a little stick figure. He was already nine, but weighed only 35 pounds. He was coughing and had a fever, and so was thought to have pneumonia. Antibiotics were prescribed, and it was suggested that he be brought back to the clinic in a couple of weeks for follow-up.

Two weeks to the day, Sanoît's mother brought him back. He was worse, a mere skeleton. This time a chest X-ray was taken, and he was diagnosed with tuberculosis.

"Am I going to die?" he asked quietly, as if curious.

ART: MICHAEL TUNNEY, S.J.

"No, you're not going to die."

Sanoît, I recall, looked doubtful. I know little about child psychology; but this boy, I believe, had seen enough deaths to conclude that he was not going to survive tuberculosis. And why shouldn't he think that? Tuberculosis almost killed his mother; it had taken the lives of many he knew.

Of course, Sanoît did not die. He recovered beautifully, "almost as if he had a treatable infectious disease." The same cannot be said for the other "disposable" people. Fifty years after the introduction of almost 100 percent effective combination therapy, tuberculosis remains the world's leading infectious cause of preventable deaths. If the World Health Organization is correct, tuberculosis last year killed some 3 million people—more than died from complications of H.I.V. infection and perhaps more than have died in any one year since 1900. This has happened in almost complete silence, in large part because tuberculosis victims are usually poor. This point has recently been underlined by Lee Reichman, who notes that, if tuberculosis were taken seriously, discussions about it "would have to be moved to the local football stadium to accommodate all interested parties."

In the name of cost effectiveness we cut back health benefits to the poor. We miss our chance to heal.

Although calls for patients to clean up their acts also ring out in the tuberculosis literature, it is again clear that those least likely to "comply" with treatment recommendations are precisely those least able to comply. Thus are the poor—people like Sanoît and his mother—put at risk of tuberculosis, at risk of having no access to treatment and at risk of being blamed for their own misfortune and for infecting others.

Maribel and the Logic of Cost Effectiveness.

Maribel is a 24-year-old woman who formerly worked as a nurse's aide in a public health clinic in Lima, Peru. She used to love to care for children, she told me, especially those with tuberculosis, since they were often shunned. When I first met her last summer, Maribel was gravely ill with multidrug-resistant tuberculosis (MDRTB). She was emaciated, wasted by daily fevers and drenching sweats. Part of her right lung, destroyed by the disease, had been removed; the other was severely affected. She'd been told nothing further could be done. In keeping with World Health Organization recommendations, it had been determined that the treatment of MDRTB is not "cost-effective" in poor countries.

Maribel, needless to say, did not much appreciate this logic. There were, in fact, antibiotics to which her infecting isolate was susceptible. When she received them last September, she soon began to respond. ("It's almost as if she had a treatable infectious disease"). In January she had been able to attend a picnic at the house of another patient. She was even able to dance a bit and seemed to enjoy her first outing in years. Maribel seemed particularly pleased that her treatment and improvement occurred against a tide of official opinion. She announced her intention to prove this opinion misguided.

So imagine my dismay when the Haitian priest with whom I work poked his head into the clinic and announced that my Peruvian co-workers had called Port-au-Prince looking for me. Maribel was, he reported, "on the brink of death." My advice was requested by colleagues in Lima. But it takes four hours to reach a telephone in Port-au-Prince, and there was no way I could leave the patients in Cange. Surveying the crowded ward, the priest observed, "It looks like all we can send Maribel is our prayers."

That Saturday the team in Peru looked for a clinic that could provide the intensive care that Maribel would require if she was to survive the weekend. Some clinics simply refused to admit a patient with MDRTB. Others refused to keep her on her anti-tuberculosis medications. Finally a deal was struck, and Maribel was soon receiving mechanically assisted ventilation in a posh Catholic clinic in central Lima. News of this reached me by the radio linking the clinic to Port-au-Prince.

I marvelled at what was happening. It was easy to see a complex network of concern reaching from Lima north to Boston, and back down, by an erratic radio, to a small village in rural Haiti. The next day a Mass was offered for Maribel. The priest had never seen mechanical ventilation, but prayed for her to "respond quickly and breathe on her own."

This is precisely what Maribel did. Shortly after her intubation, she was diagnosed with acute bacterial pneumonia. She responded to antibiotics and, increasingly feisty, "self extubated" a few days later. A couple of days after that, I was by her side. She was, she declared, *un milagro,* a miracle. She was determined to get better, and did not fail to mention that her survival would be a rebuke to those who declared cases like hers to be hopeless or their treatment not cost-effective.

Opposition to the aggressive treatment of MDRTB in developing countries is justified as public-health *Realpolitik*, but careful systemic analysis calls into doubt such received wisdom. Although there is obvious confirmation of our failure to confront tuberculosis effectively, there are few data to support the hypothesis that there are insufficient means to cure all tuberculosis cases everywhere, regardless of susceptibility patterns. Rather, the degree of accumulated wealth is altogether unprecedented, but this accumulation has occurred in tandem with growing inequality. Simply following the money trail reveals both the degree of available capital and also the degree to which resource flows are transnational. In 1996, Peru made debt payments, largely to U.S. banks and the international financial institutions, of $1.25 billion—over 14 percent of total Government expenditures. Projections for the coming year are that debt payments will total $1.85 billion, which will represent 18.7 percent of all Government outlays. In the last three decades, the gap between rich and poor countries has doubled.

If we fail to resist the current trends, we risk sapping biomedicine of its vast power and ourselves of our humanity.

In the global era, we often engage in fraudulent analyses of where the boundaries are of our "communities" and where they fit in larger social webs. If I were one of the "Masters of the Universe," to use Tom Wolfe's phrase, I'd try and get folks like us to adopt a motto such as "think globally, act locally." In terms of analysis, those who direct modern commerce are far ahead of us. They understand the artificiality of borders; they exploit the whole world. Meanwhile, the forces of healing are trammeled by parochialisms of place and creed.

Maribel is still sick with a terribly resistant strain of TB. Our efforts on her behalf may ultimately fail, but they will not have failed to call into question the cynical calculus by which some lives are considered valuable and others expendable.

Health Care "Reforms" Versus Progress With Justice.

How do these three stories fit into the local moral worlds of our clinics and hospitals? All illustrate the fact that with all our technological power, our magnetic resonance scans and our protease inhibitors, we allow not just the continuation but rather the *entrenchment* of inequalities. The justification for this sad state of affairs is usually economic. We're told that we live in a time of "shrinking health resources." But is this really so? Look at profits in the managed care companies. The Wall Street Journal described in December 1994 these companies as "money machines so awash in cash that they don't know what to do with it all." The New York Times noted in April 1995: "Penny Pinching HMO's Show Their Generosity in Executive Paychecks." The C.E.O. of one managed care company received a salary of $370,604 and stock options worth over $15 million; other, more dramatic examples were offered. One detractor of managed care, Leon Eisenberg of Harvard Medical School, asks: "Where did the money come from? Was it simply from 'greater efficiency'? Or did a significant part of it come from care not given?" Eisenberg trenchantly concluded, "In a profit-driven, competitive market place, managed 'care' is an oxymoron."

Again, perhaps it is we physicians who need to clean up our acts. Increasingly, the inequalities that we are called to countenance are inimical to good medicine. Even stop-gap measures, like the Federal program designed to make AIDS and tuberculosis therapies available to the poor, are under heavy fire from politicians who guess, perhaps rightly, that they and theirs are never likely to need such drugs.

In the face of cheek-by-jowl bounty and penury, where are the prophetic voices in medicine? Instead of having access issues front and center, we have foggy-minded critiques of technology. Take a look at "medical ethics," a staple of medical school curricula. What is defined, these days, as an ethical issue? End-of-life decisions, medico-legal questions of brain death, organ transplantation and medical disclosure dominate the published literature. In the hospital, the "quandary ethics of the individual" constitute the bulk of discussion of medical ethics. There is dead silence in the realm of medical ethics when it comes to *access* for poor people, especially those who, like Brenda and Sanoît and Maribel, can be hidden away.

Some involved in ethics would have you believe that technological advances are in and of themselves bad. I believe the Luddites are dead wrong. We should all have access to the fruits of modern technology, especially those who most need it. As health care "reforms" move forward, this technology is increasingly at the disposal of those who can pay for it, not of those who need it most. This, I would argue, is the great drama of medicine at the end of this century. And this is the challenge for all people of faith and good will in these dangerous times.

Rediscovering Social Justice.

It stands to reason that, as beneficiaries of growing

inequality, we don't like to be reminded of misery and squalor and failure. I recently read of attempts in England to get rid of the cross. Too disturbing. Inappropriate. A downer. Other symbols were suggested. How about a candle? A fish? Anything other than this stark reminder that people are being crucified throughout the world.

Yet the voices, the faces, the suffering of the sick and the poor are all around us. Can we see and hear them? Well-defended against troubling incursions of doubt, we the privileged are precisely the people most at risk of remaining oblivious, since this kind of suffering is not central to our own personal experience.

Can we tune in to the prophetic voices in our midst? One of my students, Anthony Mitchell, is a preacher; and he recently shared with me one of his sermons. Delivered last Dec. 29 at the Greater Piney Grove Baptist Church in Atlanta, Ga., the homily is titled "Who Has the Last Word?"

> We live in a time where Herod is in control.... If you stand up and do as John the Baptist did, say a few simple words—such as "That is not right; this is not how it should be done; this is not how we should treat one another; this is not how we should live"—you are risking death. Sometimes we forget that the Christian life is a risky life, a life that might cost you your own life. This is the context of the text, and also the context of a miracle.... This is the Gospel. This is where it is preached, in dangerous times.

These are indeed dangerous times, especially if one is engaged in efforts to serve better the destitute sick. In the name of cost effectiveness we cut back health benefits to the poor, who are more likely to be sick than those who are not poor. We miss our chance to heal. In the setting, we are told, of scarce resources, we imperil the health safety net. In the name of expedience, we miss our chance to be humane and compassionate.

Herod remains in control, but this is also the context of the miracle. That is, it is in precisely such contexts that we have the privilege of reasserting our humanity. Against a tide of utilitarian opinion and worse, we are offered the chance to insist, this is not how it should be done. Indeed, this is always what healers were called to say, but now the stakes are even higher. At the close of the millennium, the world is a very different place than when the prophets roamed the land. Medical technology has changed. We have increased diagnostic capabilities, great laboratories and effective medications for a host of diseases.

Certainly these developments are expensive. Certainly excess costs must be curbed. But how can we glibly use terms like "cost effective" when we see how they are perverted in contemporary parlance? You want to help the poor? Then your projects must be self-sustaining or cost effective. You want to hurt the poor? Hey, knock yourself out; the sky's the limit.

Similar chicanery is used with a host of other terms, ranging from "appropriate technology" to "community." Through analytic legerdemain—the world is composed of discretely bounded nation states, some rich, some poor, and each with its unique destiny—we are asked to swallow what is, ultimately, a story of growing inequality and our willingness to condone it.

Is this the best we can do? Perhaps we need a new lexicon for this "new health care environment," or perhaps we need to rediscover an old one. A compelling lexicon of social medicine must be linked to a return to social justice, to a struggle against the tide of opinion. Bryan Stevenson of Alabama's Equal Justice Initiative is "convinced that justice is a constant struggle, and where you find no struggle, you find no justice." Although Stevenson is referring to law, the same holds for modern medicine. If we fail to resist the current trends, we risk sapping biomedicine of its vast power and ourselves of our humanity. If we lived in a utopia, simply practicing medicine would be enough. But we live in a dystopia. Increasingly, in this "new environment," inequalities of access and outcome characterize medicine. These inequalities could be the focus of our collective action as morally engaged members of the healing professions, broadly conceived. For we have before us an awesome responsibility—to prevent social inequalities from being embodied as bad health outcomes. We do have the technology.