



Questioning health and human rights

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In the early 1990s the World Health Organization (WHO) decided that it wanted to eradicate tuberculosis. This would be no small task, given the fact that multi-drug resistant TB (MDR-TB) was again gaining ground, primarily in Third World countries. In order to curb the spread of MDR-TB, many medical NGOs—including my own, Médecins Sans Frontières (MSF)—became committed to WHO's program, which instructed that no patient should be treated unless you could expect an 80 percent rate of compliance from the population he belonged to. If previous evaluations lead to think that you were unlikely to reach this high rate of compliance, then it would be better not to treat. The idea behind the program was that doctors should refrain from treating patients rather than risk spreading MDR-TB—which would lead to the deaths of many more people.

So in the name of this eradication program, in the cause of struggling against MDR-TB, for the sake of nice statistics, MSF and other humanitarian aid groups accepted that human beings, people of real flesh and blood, ought to be sacrificed. This is a moral and practical dilemma of a kind that medical practitioners and health professionals face all the time while working in the field. Who are we to decide who should live and who should die? For me, the terms of this dilemma ought to be posed in practical and political terms, rather than in terms of human rights. The issue of sacrifice is one that ought to be determined by the community, not by scientific experts, and the language of human rights is too vague to help in these determinations. Human rights claims often conflict with one another; no sooner has one been evoked than another, contradictory one, emerges. This is because a list of human rights is not a consistent and coherent entity. Even worse, WHO's definition of a "right to health" is hopelessly ambiguous. I have never seen any real analysis of what is meant by the concept of "health" and "health for all," nor do I understand how anyone could seriously defend this notion. For WHO, health does not consist of the absence of disease or handicaps; it is the state of complete physical, mental, and social well being. It has nothing to do with concrete persons, concrete diseases, or concrete explanations about health.

Nor does this definition of a "right to health" help medical practitioners make decisions in difficult cases of when to treat and how to treat, as in the MDR-TB example. Guiding these decisions are two prominent, but very different, models. The first, which one might call the "public health model" stresses the promotion of overall public health standards. The second, which one might call the "humanitarian model" stresses the value of direct treatment of existing medical conditions. There is thus a conflict of values informing the decisions of health professionals—values of general perfect public health standards versus values of direct treatment and direct help to concrete persons in need of medical attention.

According to the public health model, the most important factors in decision-making should be how badly off the people affected by these conditions are in absolute and relative terms, how costly prevention or treatment would be, and how much patients would benefit from particular policies. This approach is oriented toward bringing about the best long-term health outcomes. If treatment is the best way to contribute to these long-term outcomes then one should treat, but if denying medical care to people who need it now is the best long-term strategy, then no treatment should be given. This model is generally accepted by WHO and clearly informed their policies regarding TB. As if the future could be reduced to epidemiological patterns... Because TB patients need special follow-ups for at least eight to ten months, the public health threat is increased by so-called defaulters—a word that has moral overtones, but that refers to those who abandon treatment prematurely. Defaulters threaten other members of the community because they might develop MDR-TB.

The humanitarian model asserts that our primary obligation is to give direct medical treatment to people who require medical attention. Essentially, we should try to treat as much as we can, regardless of what effects this may have in the future. It is the role of the medical practitioner to answer to patients' demands first, within the limits of his abilities. This implies that the practitioner must first seek to understand the always complex interests of the particular patient he is examining. Till 1994, MSF clearly applied this model by encouraging its medical teams to treat TB outside of the procedures promoted by the WHO—though increasing pressure from the international aid community has made this increasingly difficult. Then, in 1994, a new TB guideline was issued by MSF referring explicitly to WHO's declaration on the eradication TB as a public health priority. This book came out without any internal debate, which shows that the relevance of a "scientific" approach of the cost of human life imposed itself as an evidence, not as a question. But for the last two years, fortunately, things have been changing, slowly.

The humanitarian model is preferable to the public health model on both moral and practical grounds. Medical practitioners should not be understood as the representatives of society or of its *supposed* interests towards patients, as the public health model requires. Instead, their role is to deal individually and sensitively with persons who are ill. Moreover, the public health model falsely presupposes the exactitude and validity of epidemiological predictions. I have a deep skepticism toward epidemiological prediction. Though epidemiology certainly has value, it is often used in a scientifically unsustainable way as a "proof" that certain policies will lead to certain outcomes. One simply needs to observe the number of correlations that are insidiously supposed to indicate causal relationships and the manner that these supposed causal relationships are then translated into policy prescriptions, to understand empirical and moral implausibility of this model. Statistical abstractions are falsely transformed into certainties, and some modes of treatment (such as the anti-TB treatment program that should have been pursued by MSF in Angola) become thereby taboo.

Epidemiological “certainties” also create the illusion that obstacles to the treatment of disease are insurmountable, when often what is really lacking is a commitment on the part of politicians and the medical community. WHO, for instance, preferred to stick with the strategy of disease eradication, even if it were to mean embracing a policy of human sacrifice instead of recommending resumption in TB research. Yet TB is like any other infectious disease—it evolves genetic mutations that require new antibiotics. But nobody has bothered to raise this issue because, of course, TB patients are poor and therefore do not provide a profitable market for drugs. These political and economic conditions are simply assumed as a fixed background by the public health model.

The public health model would require us to exchange corpses against would-be corpses. To me, that is really a strange swap. It is something that morally and medically—and I would say simply humanly—is unacceptable. Does taking a human rights, a “right to health,” approach on this issue of MDR-TB help us adjudicate between the merits of the public health and the humanitarian model? I would say no.

A real issue, a practical issue that might be defended from a human rights perspective is the right to health care, instead of a right to health. I would like to see activism focus on the delivery of health care, since this can have concrete consequences for concrete beings. Disease is an inalienable fact of life, but lack of access to appropriate medical care is not. Is this really a “human rights” issue, however? I’m not so sure. But it is at least a common concern that I think we can all agree upon.

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