

FROM HEALTH OR HUMAN RIGHTS TO HEALTH AND HUMAN RIGHTS: WHERE DO WE GO FROM HERE?

Nahid F. Toubia, M.D.

*This text was presented at the First International Conference on
Health and Human Rights at Harvard University,
Cambridge, Massachusetts, USA, September 24, 1994.*

For many, it seems only sensible—and fairly obvious—that health *is* a human right. But such a conviction is still not commonly held among the majority of those working in the health field. Modern medicine and its powerful institutions, well established in every country in the world, leave us with a heritage of professional patronage in which decisions affecting health are the prerogative of physicians and senior health workers. At best, health is considered a basic service to be delivered by governments and physicians, rather than a basic right of individuals and communities.

Adoption of the human rights paradigm has the potential to revolutionize the health field. The human right principle that “all human beings are born free and equal in dignity and rights” is a powerful concept in spite of its simplicity. By applying the principle of equality to health, we have no choice but to examine the relationship between the individual and all those who have power to affect his or her health.

In general, the medical literature reports only on disease resulting from “natural” causes, while physical and psychologi-

Nahid F. Toubia is Associate Professor of Clinical Public Health, Columbia University School of Public Health. Please address correspondence to Rainbow Outreach Action Information for Bodily Integrity of Women, 24 East 21st St., 5th Floor, New York, NY, 10010, USA.

cal ill-health resulting from violations by the state, society or the family are rarely cited. The spread of AIDS among customers of commercial sex workers is usually couched in epidemiological terms of vector and carrier, while those social and political conditions that force young girls into virtual slavery to become these vectors—and the ultimate victims of AIDS—are rarely acknowledged. Domestic violence, with its obvious effects on health, has only recently and in very few countries been considered a health issue. Female circumcision, or female genital mutilation (FGM), was once considered only a health hazard but is now discussed in terms of a girl's right to preserve her body and sexuality intact. Health policies targeting members of ethnic or racial minorities without appropriate consultation are often reported as genetic or biological comparative studies, and not as the violation of rights that they frequently are.

In the field of preventive medicine, we are often faced with the difficult choice between fostering public good and sustaining individual choice. Subjects that come to mind include tobacco smoking, alcohol and drug abuse, and the effect of media images on women's psychological and physical health, among others. Of particular prominence in this area is the largest international preventive health effort: namely, family planning programs and their potential human rights violations. Forced abortions and sterilizations, abuse of injectables, implants and other provider controlled methods have all been reported.

Two other areas of health rights issues are environmental damage and pollution, which have been shown to put community health at risk. While a degree of economic development is vital to improving health standards, there exists a potential conflict between economic development/prosperity and health rights.

In curative health care, most doctors and other health professionals are trained to believe that they know what is best for their patients. Patients' rights to full information and decision-making power decrease in direct correlation with lowered social, economic or gender status. This is more dramatic in countries in which illiteracy is high, public health information is practically nonexistent, and the legal system is too weak to be utilized favorably. Removal of diseased or non-diseased bodily organs without patient permission and use of experimental procedures without informed consent are not uncommon.

Methods

The field of health and human rights will, in many cases, examine long-standing and recognized health issues from a new angle. In other cases it will look at new and unrecognized issues of concern to health professionals. The use of the human rights paradigm in health will require combining health knowledge with knowledge of law and ethics.

Of course, many human rights principles are already outlined in international and national laws. But increased understanding of, and familiarity with, international laws and treaties, as well as with constitutional laws, will mean closer collaboration between the health and legal professions in the future.

In order to develop new human rights principles or revise old ones, the health and human rights field will have to go to the source: ethicists and thinkers, both religious and nonreligious, from all cultures. Their recruitment will be necessary in advancing the field of health and human rights beyond existing laws and treaties.

The human rights field operates in such a way as to protect the individual from the vicissitudes of power that impact his or her life. In the field of health, this power may be the state; international policies and programs; multinational and local drug companies; the medical establishment; and finally, the family and community.

Individuals and groups who wield least power need increased social and legal protection. Particularly vulnerable are women, the illiterate and poor, the disabled, ethnic and racial minorities, indigenous people and children. In our research and analysis of health and human rights, we must be particularly mindful of the vulnerability of these groups, and of other power imbalances that may prevail in a particular society.

A major and common conflict that should be addressed constantly by those developing rights principles is the conflict between *individual* and *group* rights. Because human beings live in community with one another, there must be a limit at which individual rights end and group rights begin. On the other hand, group rights are often invoked to suppress individual freedoms and the right to self-determination. Human rights professionals must invoke a dialogue between citizens of Western societies (particularly in the United States, where individual rights are

asserted to the maximum) and citizens of Eastern societies (where communal and group values predominate). Each system has its benefits and drawbacks, and both have valuable contributions to make to global human rights principles.

This brings us to another major conflict in the human rights field: that of *universality* vs. *cultural relativism*. Undoubtedly, many cultures differ as to what constitutes a right, a voluntary common courtesy, or a violation. To use a benign example with few moral overtones, consider “noise” as a pollutant and a hazard to mental and psychological health. In certain societies, noise generated by an individual inside his/her home is part of the right to privacy and cannot be interfered with. In other societies, not generating noise that may affect one’s neighbor is part of common decency. In yet another society, the timing and level of noise generation is regulated by law. When noise generation is part of religious rituals, the situation becomes even more complicated.

The best approach to such cultural differences is to involve individuals from different cultures and religions committed to establishing human rights principles in a constructive process—one that transcends differences and emphasizes the human rights principles common to all cultures and belief systems. Those developing the mechanism for such a process must consciously curtail the prevailing biases in Western cultures, including a certain degree of dominance in the human rights field and attitudes of cultural superiority.

The Way Forward

Better definition of health rights concepts

For example, what do we mean by *guardianship*, and to what extent is the guardian of a minor allowed to make decisions on that minor’s behalf? The issue of circumcision for both female and male children may be a good example to pursue. For another, the age of consent itself needs to be better defined and standardized.

Agency is another concept that needs to be discussed. To what extent can professionals assume themselves qualified agents to make health decisions? On the other hand, given the highly specialized and vital nature of medical knowledge, can physicians in good conscience forego their responsibility both to change

unhealthy behavior and to use their critical judgment to improve their patients' health? Where is the balance? Is finding the balance a matter of training or legislation or both?

The concept of agency is also important when dealing with disability, both physical and mental. Very often, organizations acting on behalf of disabled people make decisions without considering their clients' needs and desires. Physical disability is often interpreted as meaning inability to make decisions; the desire to protect those with mental disability has often resulted in violation of their rights.

When agency and guardianship are taken over by the state or the courts, laws must be clear so that these entities also may not use their power to violate the socially vulnerable. Such has been the case for single mothers on welfare in the United States.

Informed choice is a concept frequently discussed in clinical terms, and has not been sufficiently defined in rights terms. Informed choice in clinical research, in family planning, and in a patient's method of treatment for any disease must all be explored.

Consent is another concept that should be explored, on the basis of age, ability to make sound decisions and presence of overt or subtle coercions. Probably the most difficult to define, social and economic coercion could be the strongest and most common forms of coercion worldwide.

Research

Both at the local level in communities and in the broader realm of health service delivery, exploration must be done of the operational concepts of health and human rights within the specificities of different cultures. Comparative and cross-cultural research and reporting would also be useful in developing common ground for discourse and policy-making.

- *Involvement of health professionals through their unions and associations.* This step is vital if any change in attitudes is to take place.
- *Legislation for health rights at national and international levels in two ways.* First would be laws to prevent violations; and second, laws to assert health rights and regulate health services.

- *Development of national and regional capacities on health and human rights.* This will go far toward building a network and encouraging information-sharing between countries and institutions.
- *Development of health rights monitoring mechanisms at national and international levels.* This will help to ensure applications of principles, and create the pressure to bring about change.
- *Last but most important, education on health and human rights.* The public must become aware of the message of health rights; the medical and nursing schools given guidance on how to observe and promote these rights; and policy makers encouraged to create an environment in which health and human rights can take root and blossom.

Finally I would like to thank the Harvard School of Public Health for taking the first step towards such an education. It is to the great advantage of the field of health and human rights to be pioneered by such a renowned and prestigious institution and should undoubtedly contribute to its future success.