

Health and Human Rights 1

History, principles, and practice of health and human rights

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Individuals and populations suffer violations of their rights that affect health and wellbeing. Health professionals have a part to play in reduction and prevention of these violations and ensuring that health-related policies and practices promote rights. This needs efforts in terms of advocacy, application of legal standards, and public-health programming. We discuss the changing views of human rights in the context of the HIV/AIDS epidemic and propose further development of the right to health by increased practice, evidence, and action.

Introduction

Blatant violation of human rights affecting the health of both individuals and populations continues. Examples include the torture of detainees in Abu-Ghraib prison in Iraq;¹ systematic rapes and murders in the Balkans;² Rwanda,³ Chechnya,⁴ and Darfur;⁵ physician involvement in torture,⁶ botched executions;⁷ inhumane experimentation;⁸ and questionable interrogation techniques in the so-called war on terror.^{9,10} Such violations of human rights can be engineered by or endorsed by governments, institutions of power, and individuals. These deplorable violations exist alongside more subtle activities that also have severe and longlasting effects on health and human rights such as absence of basic health-care systems;¹¹ policies keeping medicines unaffordable;¹² and tolerance of discrimination against groups such as injecting drug users,¹³ people with mental-health disorders,^{14,15} illegal immigrants,¹⁶ or homeless people.¹⁷ The continuing and foreseeable absence of access to effective care for most people living with most diseases in poor countries can also be viewed as a violation of human rights.¹⁸ Therefore human rights should be imperative in delivery of care and implementation of public-health programmes.

Three main relations between health and human rights exist: the positive and negative effects on health of promotion, neglect, or violation of human rights; the effect of health on the delivery of human rights; and the effects of public-health policies and programmes on human rights.¹⁹ Despite the advances in the study and advocacy of health and human rights we still do not fully understand the nature of these relationships, how they interact, or their value to medicine and public-health practice. In this article we address the public health aspects of these relations, and highlight where further research and action are needed.

A brief history of health and human rights

Since the Nuremberg trials and the creation of the UN more than 50 years ago, interest in the association between health and human rights has grown. Until the beginning of the AIDS epidemic in the 1980s and the end of the Cold War, these two issues evolved along parallel but distinctly separate tracks,²⁰ perhaps as a consequence of the state-centric (ie, greater political

concern for general state and public interests than for specific individuals or communities) view of the world that prevailed in the second half of the 20th century. However, governments have a responsibility both to deliver essential health and social services, and to enable people and their families to achieve better health by respecting human rights.

In the past 20 years, the HIV/AIDS pandemic and reproductive and sexual health concerns have been instrumental in clarifying the ways that health and rights connect. These issues encompass law and policymaking, and have established the roles and boundaries of responsibility held by state and non-state stakeholders for the conditions that constrain or enable health and for delivery of health and related services.²¹ The first worldwide public-health strategy to explicitly engage with human rights concerns took place in the late 1980s, when Jonathan Mann directed the Global Program on AIDS at WHO.²² Although this strategy was partly motivated by moral outrage at abuses suffered by people living with HIV, the inclusion of human rights was primarily because evidence was emerging that showed that discrimination was driving people away from prevention and care programmes.²³

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Defendants at Nuremberg trial

Panel: The right to health in international law

The right to the highest attainable standard of health—often referred to as the right to health—is most prominently connected to the ICESCR.⁴³ It stipulates that:

The states parties to the present covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The steps to be taken by the states parties to the present covenant to achieve the full realisation of this right shall include those necessary for:

- (a) the provision for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child;
- (b) the improvement of all aspects of environmental and industrial hygiene;
- (c) the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases;
- (d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.

Elimination of such discrimination was expected to encourage people not only to fully exert their rights, but also to come forward for voluntary counselling, testing, and treatment of opportunistic infections. Uptake of these services would in turn help them safeguard their dignity, improve their health and wellbeing, and motivate them to adopt behaviours that would restrict further spread of infection. That this strategy—upholding human-rights principles—was set forth by WHO, an inter-governmental organisation with responsibilities for promotion of rights conferred by the UN Charter, placed it in the realm of international law.²⁴ As a result, governments and intergovernmental organisations were made publicly accountable for their public-health and human-rights actions (or inactions). Since the 1980s, responses to the HIV pandemic have drawn attention to the rights of the most vulnerable people and societies, and the need to prevent discrimination in both law and practice.²⁵

A series of international conferences held by the UN, beginning in the early 1990s, further solidified the dual obligations of governments to the health and human rights of their people.²¹ These conferences brought together emotions and values, but also the experiences of local, national, and international practitioners (physicians, nurses, and other health workers), advocates, and policymakers. The 1997 Program for Reform, designed by Kofi Annan, then UN Secretary-General, highlighted the promotion of human rights as a core activity of the UN, which was another important step in moving issues of health and human rights from rhetoric to implementation, action, and accountability.²⁶

Almost all development agencies, organisations and UN programmes,²⁷ albeit to varying degrees of success,

now pay attention to human rights in their work in health. Additionally, many governments are beginning to integrate their human rights obligations into their health-related activities, both in high-income and low-income countries.²⁸ In addition to members of affected populations, medical practitioners have also contributed to bringing human rights into health through their advocacy and practice.^{29,30} Nonetheless, integration of human rights in health efforts clearly still has a long way to go.

Human rights and health policy

The links between human rights and health are best understood by referring to the preface to the WHO constitution, which states that health is the “state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity” and “the highest attainable level of health is the fundamental right of every human being.”³¹ Governments are therefore responsible for enabling their populations to achieve better health through respecting, protecting, and fulfilling rights (ie, not violating rights, preventing rights violations, and creating policies, structures, and resources that promote and enforce rights).³² This responsibility extends beyond the provision of essential health services to tackling the determinants of health such as, provision of adequate education, housing, food, and favourable working conditions. These items are both human rights themselves and are necessary for health.^{33,34} The relation of people with their environment is complex and the fulfilment—or absence—of human rights and their effects on the main determinants of health needs much investigation.

Human rights encompass civil, political, economic, social, and cultural rights. These rights are cast in international law, through many treaties and declarations, beginning with the UN Universal Declaration of Human Rights in 1948.^{35–41} These documents highlight the importance of promotion and protection of human rights as a prerequisite to health and wellbeing. Although one can devote attention and resources to one specific right, or to a category of closely connected rights, all rights are interdependent and interrelated,⁴² and as a result individuals rarely suffer neglect or violation of one right in isolation.

Economic, social, and cultural rights, such as education and food, are relevant to health, as are such civil and political rights as those relating to life, autonomy, information, free movement, association, equality, and participation. Recognition of the legal and political obligations that connect economic, social, and cultural rights, as well as civil and political rights, continues to grow. The right to the highest attainable standard of health therefore builds on, but is by no means limited to, Article 12 of the UN International Covenant on Economic, Social, and Cultural Rights⁴³ (ICESCR; panel). It transcends almost every other right.

Although the right to health forms the legal basis for much of the present work in health and human rights, if written today it would probably place greater emphasis on health rather than sickness and on health systems rather than provision of medical care. Addressing the effects of discrimination, gender-related or otherwise, on health and delivery of services is well covered by other rights, again showing how human rights are intertwined.⁴⁴

The legal obligation of states to respect health-related rights is only one part of the picture, because rights are also used to guide policies and programmes for health and wellbeing. They enable a broad response to health and development by national and international stakeholders with responsibilities that reach beyond the health sector. Thus, although international treaties, enriched by declarations and related documents, have legal implications, they importantly can also inform the development of policies and programmes in all states, whether or not a state has signed to be legally bound by the relevant treaty.

Applying human rights to health

The idea of health and human rights as a subject of study is fairly new, and we need to recognise the different ways in which advances in health and human rights can be achieved. Human rights feature in many different ways in the health work of international non-governmental organisations, governments, civil society groups, and individuals. These ways can be broadly categorised as advocacy, application of legal standards, and programming (including service delivery).⁴⁵ Some stakeholders use one approach; others use a combination in their work. We use HIV/AIDS as the main example to show the effectiveness of these approaches, although examples in reproductive health,⁴⁶ mental health,⁴⁷ disability,⁴⁸ neglected diseases,⁴⁹ or other serious health issues could effectively serve as illustrations.

Development of new treatments and the investment of substantial and increasing resources to offer these treatments to people living with HIV have resulted in access to treatment and care for some people. These people gain substantial duration and quality of life, allowing them to participate actively in political, civil, economic, social, and cultural activities. By contrast, despite global initiatives to increase access in resource-poor places, progress has been slow and remains below expectations.⁵⁰

Advocacy and bearing witness

The model of health and human rights is often used in campaigns for changes in health-related policy and practice. Early campaigns as a response to some governments' complacency in dealing with AIDS illustrated the success of this approach and set a precedent for health campaigns around the world.^{51,52} The focus of activism is often on recognition and exposure of governmental

obligations, establishing the amount of government action or inaction that contributes to existing violations, looking at how a government deals or does not deal with identified problems, and recommending solutions.

Since the turn of the century, the pharmaceutical industry has lowered the price of antiretroviral drugs in low-income countries to less than ten percent of their cost in 2000,⁵³ mainly because of pressure framed around the right to access treatment, exercised on them by non-governmental organisations, the mass media among others. Although this development brought opportunities for greater access to antiretroviral drugs, national and international work is still needed for these drugs to reach the people who need them, especially those living in low-income and middle-income countries.⁵⁴ The most recent international agreements to provide universal access, the human rights obligations of states to make such services available, and the obligations of wealthy countries to engage in international assistance and cooperation⁴⁰ puts additional obligations on wealthy countries to help poor ones to achieve these goals. These obligations can be used as an effective advocacy strategy.

Médecins Sans Frontières and Médecins Du Monde have both shown the important parts that individual health practitioners can play in international crises. These groups were founded on the premise that health practitioners and the communities sponsoring them have an international duty to maintain health, especially that of disadvantaged people living in regions affected by warfare or natural disasters. Such principles have grown to include the response to HIV/AIDS and situations of chronic extreme poverty.⁵⁵ These organisations were born of civil society in the late 1960s, inspired by the belief that clinicians, other health professionals, and volunteers could improve the health of poor and vulnerable people whose governments were failing to do so, either by design or incapacity.

Although not initially intended as the launch of a health and human rights movement, the emergence and growing influence of these groups and those that have followed, has drawn attention to the universal value of health and the duty of care providers, other humanitarian workers, and the international community to intervene when human rights are ignored. A recurring dilemma confronting these organisations is whether sustainable health action should be associated with documentation and denunciations of witnessed human rights violations, as these activities could both limit their ability to provide health services to the populations they serve, and jeopardise the safety of their workers.⁵⁶ Of note, the international appeals from non-governmental organisations and some relief agencies, in such situations as that of the Great Lakes area in Africa in the 1990s, in which a late and weak international response resulted in greater chaos and many casualties that could have been prevented.

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Doctor from Médecins Sans Frontières examining a child in Darfur—aid agencies such as Médecins Sans Frontières have an important role where human rights violations take place

Application of legal standards

In a strictly legal sense, applying human rights to health means using internationally accepted and nationally agreed upon norms, standards, and accountability mechanisms within health-care systems and in the work of national and international health, economic, and developmental policymakers.⁵⁷ Legal mechanisms can sometimes also provide channels of redress for individuals whose rights have been violated in the context of public-health interventions. In South Africa and several Latin American countries, the human rights provisions of national constitutions (eg, the rights to life, to health, and to benefit from scientific progress) have been interpreted to enable claims for access to antiretroviral medicines.⁵⁸ In Latin America, individuals supported by non-governmental organisations, have undertaken 13 successful lawsuits to date against their governments for access to antiretroviral drugs. In fact, in Argentina, one such success resulted in assurances of provision of care for 15 000 people.⁵⁸ Treatment Action Campaign in South Africa used the courts to ensure that the government was ordered to provide programmes in public clinics for reduction of mother-to-child transmission of HIV.⁵⁹ Although these efforts have resulted in positive changes in the law, advocacy is still needed to move these obligations into practice; thus emphasising how advocacy, and application of the law are interrelated.

Rights in delivery of care and programming

Even though many organisations describe their approach to health as rights-based, we have no one definition of what this entails.⁶⁰ All such organisations seem generally concerned with ensuring that vulnerable populations are provided with the services that they need, but in practice these organisations have used different approaches to

the incorporation of rights into different stages of the programming cycle; from situation analysis, to planning, implementation, monitoring, and assessment.⁶¹ The core components of rights-based approaches include: examining the laws and policies under which programmes take place; systematically integrating core human rights principles such as participation, non-discrimination, transparency, and accountability into policy and programme responses; and focusing on key elements of the right to health—availability, accessibility, acceptability, and quality when defining standards for provision of services.⁶⁰

HIV testing serves as a useful example to illustrate the link between health and rights in programming. Although voluntary HIV testing has been advocated by international agencies since the start of the pandemic⁶² and is seen in many national laws and policies, the requirement for testing to be voluntary has recently been debated. The present argument is that people knowing their HIV status is more important than whether they voluntarily seek testing, because they will be able to accurately inform their partners of their HIV status, modify their behaviours, and seek treatment if available.⁶³ Consequently, an approach known as routine provider-initiated HIV testing is becoming increasingly common in health-care settings—an approach that, without careful guidance, can consist largely of assuming that patients agree to be tested unless they express objection and opt out of taking the test. UNAIDS and WHO have released guidance to support the adaption of national policies to account for this new trend.^{64,65}

This seemingly well-intended approach will need careful monitoring and assessment to ascertain whether HIV tests are being routinely offered or routinely imposed, and whether in either case, the individual has informed choice and power to opt in or opt out of being tested.⁶⁶ Future work in this areas needs evidence, rather than ideology, to establish whether these conditions help people access HIV care services, and maintain contact with such services. Attention to principles of rights such as non-discrimination, participation of affected communities, and accountability for potential positive and negative effects of adopting routine HIV testing could help to measure its effectiveness in terms of both rights and health. When a government (most recently China⁶⁷ and Lesotho⁶⁸—and both with the support of WHO) decides to screen an entire section of the population for HIV with disregard for domestic law, human rights principles, and international norms while providing little access to care for those testing positive, we face a complex challenge. How regard for human rights translates into policy formulation, programming, and service delivery continues to be debated.^{69,70}

A rights-based approach to programming needs interventions to be implemented in ways that improve health, and that efforts to reach national and international targets, for example, in relation to the numbers of people

on treatment, do not result in the neglect or violation of human rights. Although application of human rights will not establish if priority should be given to prevention or treatment, consideration of human rights will ensure that attention is given not only to the outcomes of health interventions, but also to the ways they are implemented.²¹ For example, an increase in uptake of HIV-testing services could be due to an increase in the availability of high-quality voluntary counselling and testing services, but on the other hand it could also be due to the introduction of mandatory testing for certain population groups.⁷¹ Although both interventions would seem to lead to the same short-term outcome, without regard for the reasons behind the increase in HIV testing the problems of any strategy will not be seen, which could threaten both human rights and public health in the long term.

Concerns for the future

Government roles and responsibilities are increasingly delegated to non-state actors (eg, biomedical research institutions, health insurance companies, health management organisations, the pharmaceutical industry, and care providers) whose accountability is defined poorly and monitored inadequately. No objective measures are available of the commitment and capacity of governments to ensure that actions taken by the private sector and other players, including civil society, are informed by and comply with human rights. Likewise, as the discipline of health and human rights grows, its relevance and effectiveness will depend partly on the ability to understand cultural constraints. Even when countries commit to respect for human rights, health workers need to be educated about how to incorporate human-rights principles into their work, and this should be done equally at schools of medicine, schools of public health, and nursing schools. We expect that as the number of health professionals involved with human rights increases, the practice of health and human rights will also develop.

Steps forward

Attention to human rights can be a way to enhance the value and effects of health work by health policymakers, programme developers, health practitioners, and students. Nonetheless, three topics urgently need that further work. The first is the development of adequate monitoring instruments that measure both health and human rights concerns; the second is building evidence of the effects of application of the health and human rights frameworks to health practice; and the third is the creation of a research agenda to advance our understanding of the associations between health and human rights.

Because health and human rights is a new subject, so too are the ways to measure whether a clinical scenario or public-health decision is ultimately successful in upholding human rights. Efforts are needed to assess the

effectiveness of existing methods of assessment and indicators of human rights concerns, and the extent to which these indicators need to be changed. Eventually we will know how the incorporation of human rights can effect the effectiveness of policies and programmes.⁷² We need to gain such knowledge quickly to allow us to develop an evidence base that shows the value of attention to rights for health as well as the negative effects on health of both grievous and subtle human rights violations. Until such a time, efforts to systematically review and collate existing information about the effects of human rights on health should be recognised as an urgent need.^{47,73}

Public-health efforts that consider human rights are more likely to be effective than those that neglect or violate rights.^{74,75} Integration of human rights in international health systems is increasingly driven by the recognition that the respect, protection, and fulfillment of human, civil, political, economic, social, and cultural rights, is necessary—not because they are the binding legal obligations of governments, but because they are essential for improvement of the health status of individuals and populations. We need to strengthen and build upon the available information and education about human rights ideas and processes. We also need to share information and cooperate with those working on health and those working on human rights.^{76,77} This cooperation might need institutional change and capacity building within governmental systems, international organisations, civil society stakeholders, and individuals. Increased understanding of human rights is not only of value in itself, but also provides those involved in health planning and care with the necessary means to create conditions that enable people to achieve optimum health.

Conflict of interest statement

We declare that we have no conflict of interest.

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