

## Public health & human rights – Evidence-based approaches,

*Chris Beyrer & H. F. Pizer*

DOI: 10.3395/reciis.v2.Sup1.213en

*Célia Almeida*

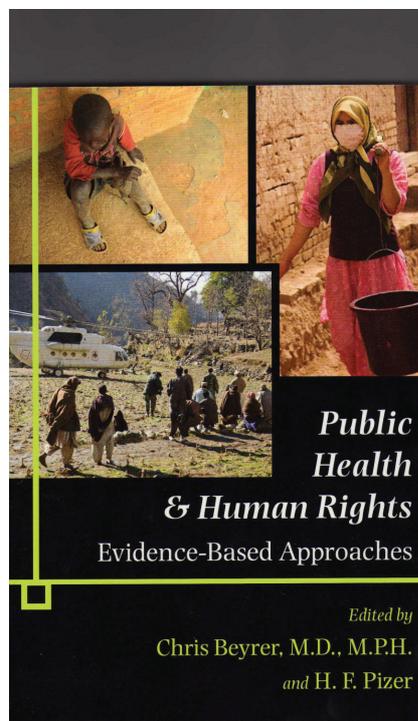
Escola Nacional de Saúde Pública “Sergio Arouca”-Fiocruz, Rio de Janeiro, Brazil  
calmeida@ensp.fiocruz.br

*Marcus Vinicius Quito*

Secretaria Executiva do Ministério da Saúde, Brasília, DF, Brazil  
marcus.quito@saude.gov.br

The book *Public Health & Human Rights – Evidence-Based Approaches*, by Chris Beyrer and H. F. Pizer, was published by Johns Hopkins University Press in 2007. Its core purpose is to discuss the links between health and human rights and to explore the methodological and policy-making issues that interrelate these two fields and thus to spur progress towards either greater respect for human rights and the preservation of human dignity or greater access to health services. It also underlines how enormously challenging is the work of understanding and demonstrating this complex connection, which although strong, is lacking in irrefutable evidence, which it is no trivial matter to produce.

The book grew out of discussions at the international seminar “Public Health and Human Rights in the Era of Aids”, organized by Johns Hopkins University in 2004. The first of the organizers, Chris Beyrer, is a medical epidemiologist and professor at the Department of Epidemiology and International Health at Johns Hopkins Bloomberg School of Public Health; he was Director of the Johns Hopkins Fogarty AIDS International Training and Research Program, working with Asia, Africa, Latin America and the Russian Federation; he was also active in conflict zones and regions suffering serious human rights violations in Asia, specifically Thailand, Burma and Myanmar, and worked with Tibetan refugees in India. The second organizer, H.F. Pizer, a writer, consultant physician and medical care consultant, has published



*Baltimore: The Johns Hopkins  
University Press, 2007*

ISBN: 978-0801886478

numerous articles and books on health and medicine. He authored the first book on AIDS for the general public (*The AIDS Fact Book*, Bantam Books, 1983), as well as other more recent books on this and related subjects. The other authors belong to different organizations working in various countries, but share the experience of, and a commitment to, combating human rights abuse.

Human rights and public health is an extremely relevant subject and the book comes at a good time. It sets itself to help answer the questions: How do human rights abuses affect the health of populations; and, conversely, how can human rights advocacy improve the health outcomes of deprived and vulnerable groups and individuals? How can this complex interaction between human rights and health be studied and analyzed better, so as to contribute to surmounting the resulting problems? And lastly, how can modern public health research techniques and instruments help document, understand and prevent human rights violations, and consequently support the right to health?

Organized into three enlighteningly interconnected parts – Cases and Contexts; Methods; and Policies – the book is lengthy and brimming with information and ideas. It is impossible in a review like this to examine in detail all the dimensions mentioned and explored in the various chapters. We will therefore attempt to summarize what we consider most important and innovative.

The first portion describes and analyzes limiting situations where not only the most basic human rights are violated, but where abuse is accompanied by dramatically deteriorating conditions of life and health, and considerable barriers to accessing health services of any kind. These cases illustrate and elucidate the various interactions between health and human rights violations, demonstrating strikingly how the State has contributed to these violations, either deliberately (under dictatorships or other authoritarian regimes), or because its key agencies are negligent, fragmented or uncoordinated.

Here the articles consider the struggles of drug users and dependents against truculent State repression in Thailand (Kerr, Kaplan, Swannawong & Wood); the problems of ethnic minorities “internally displaced” from conflict zones in Burma, the victims of violence by the governing military junta and on the border with Thailand where, unlike refugees, they have no right to any outside aid unless authorized by their respective governments (Lee, Mullany, Richards, Maung, Moo & Mahan); iatrogenic epidemics (HIV/AIDS, SAARS), which are completely ignored and denied by the Chinese government (Yanhai & Xiaorong); the total absence of rights (including the right of access to health) among sex workers in Moscow (Stachowiak & Peryshkina); and the lack of medical care and the damage done to inmates’ health in prisons practically the world over, including the USA (Mair). These case accounts also report specific successful interventions based on careful research, and on courageous political and advocacy actions, as well as the “invisible”, “secret” work of itinerant “community health agents” who have alleviated damage to health

and permitted gains – whether modest or considerable – for extremely vulnerable groups and populations (Lee, Mullany, Richards, Maung, Moo & Mahan).

Common to all these studies, the great majority in Africa and Asia, is that they describe and analyze problematical situations where any given type of violence is just one component of brutal human rights violations committed against what are already very vulnerable population groups and which form a highly complex weave in which different violations are often overlaid on one another. There are thus associations between rights abuses and extreme situations – wars, conflicts, persecutions, arbitrary treatment, official negligence or complicity; or between rights violations and illegal practices – trafficking of women, illegal immigration, forced labor, drug trafficking; or also violation of rights and human degradation – starvation, wretched conditions of life, and brutal violence of all kinds, including sexual violence.

The second, and longest, section of the book dissects the enormous problems of research methodology and the challenges researchers have to meet in the real world in searching for the evidence that marks the difference between what people say, what people know about, and what is proven; between reports, pure and simple, and incontestable facts backed by data painstakingly garnered and analyzed, and soundly prepared information. This is no easy task, because it demands a sophisticated technical endeavor, dedication and commitment to constructing a more just world, besides not being free of risks (for the research teams, field workers and the individuals themselves who are the object of study). Here too, where authors, actors and researchers confront situations of extreme human rights violations and abysmal life situations, the texts throw valuable light on what is involved in researchers’ making this important but perilous approximation to these realities, both in terms of their physical safety and the methodological issues (Lawry).

Especially interesting is the chapter that discusses using the tools of biology and of molecular genetics applied to the study of contagious infectious diseases in researching human rights violations and damage to the health of population groups (Beyrer). These tools make it possible to identify, with admirable precision, the chain of events connected with a single pathogenic agent and consequently the course of a given disease. Even though social epidemiology has long done this kind of tracking, the precision of these techniques has enabled sound scientific information to be constructed to establish incontestable links between, for instance, trans-border drug routes and severe epidemic outbreaks and spread of HIV in countries along those routes, most specifically as regards heroin smuggling – the economic base of Burma’s dictatorial government – to Thailand, China and India.

What this research reveals is how socially and politically useful the technique is: not only has it enabled the nexus between illegal activities, damage to health and

human rights to be clearly established, and furnished clear evidence of that connection, it has also nurtured advocacy endeavors in favor of international aid to these populations.

The other dimension of these studies concerns care for drug users, who are also victims of these processes: infected individuals who live along the routes or are involved with trafficking need preventive and curative care, which in most cases is not made available. In addition, the main producers of opium, the raw material for heroin, are the same ethnic minorities persecuted by the dictatorial government, and who practice subsistence agriculture in inaccessible mountain regions (Sherman, Armeattana & Celentano). Afghanistan presides over a similar situation in Central Asia, where clearly incriminating evidence is still lacking, but the same methodology can be applied (Beyrer).

The authors also stress the importance of using these tools (molecular analysis methods) in investigating the population-wide sexual crimes (soldiers committing rape or sexual abuses against civil populations) that occur in war and other conflict zones with foreign troop movements (UN peacekeeping forces, for example, drawn from different countries); but also in confirming iatrogenic epidemics, like HIV/aids, propagated among rural populations in China by sales of blood collected with a criminal lack of asepsis, and then also treated and distributed without due care. In this latter case, the technique made it possible to differentiate the virus spread among these population groups from the one identified in countries along the drug route, strengthening the argument that this was a crime concealed by the authorities (Wan Yan Hai & Li Xiao Rong; Beyrer).

The remaining chapters in this section deal basically with using population-based epidemiological studies to research the health effects of human rights violations. They emphasize the importance of surveys and field studies, together with statistical techniques, for accurate, robust evaluation of human rights abuse-related risks and indicators (Lawry). In that light, the authors argue and problematize the creative adaptation of traditional public health and social science research methods to the field of human rights and health. They argue the wide usefulness of these methods, but at the same time alert to the limits and research problems that have to be overcome in the process, particularly as regards collecting reliable data, and determining appropriate sample size and data treatment. They also emphasize the need to triangulate different methods and to use distinct data types (quantitative and qualitative), including allying various data collection techniques (interviews, life histories, focal groups etc.).

They warn that, in studies of this kind, the “socially and culturally sensitive” categories (sensitive research topics) used traditionally in the social sciences (e.g. race, ethnic origin, religion) have to be reviewed and broadened, because this type of research requires interrelating “socially sensitive” or “politically sensitive” categories with issues of law, ethics and safety (of researchers or re-

searched). They also reiterate the necessary realignment between research and intervention, where research is designed from the outset to provide support for action.

Working on extremely serious problematical situations in various different countries, these studies also highlight the decline – regarded as almost “natural” in these countries – in the production of data and indicators furnished by studies to monitor and document the alarming growth in problems of human rights violations and health damage, and they call for greater attention to this fact (Beyrer, Terzian, Lowther, Zambrano, Galai & Melchior), which certainly makes it harder to expose and prove episodes of abuse.

Another innovative study deserving comment addresses the issue of genocide, where recent advances have raised questions as to the possibility of predicting a possible genocide and ultimately of preventing one from occurring (Leaning). The author mentions three key factors that contribute to the difficulty of dealing with genocide: the United Nations Convention on Genocide is itself unclear; out of respect for national sovereignty, the international community is profoundly reluctant to intervene in any such situation; and the parameters for predicting that a genocide is about to take place or affirming that one is in progress are weak. It is this latter factor that has polarized attentions and spurred research efforts. The methods of public health and epidemiology that work with rates of morbidity and mortality in crisis situations are discussed for this purpose as one possible approach to strengthening evaluations and triggering “early warnings” that would enable advocacy on genocides that are ongoing (but not yet known about) or that are about to be put into effect. Even the Office of the United Nations High Commissioner for Refugees often reports signs of violence in a country without describing their intensity or detailing the actual situation. The study here was conducted by Physicians for Human Rights in the Chad-Darfur region, where, according to the author, the situation is one of genocide, but extremely difficult to prove.

The main controversy is over the “turning point” at which a shift occurs from the kinds of problems expected to arise from the crisis situation as such, and genocide. Retrospective historical studies reveal factors that may have contributed to genocide, but identifying them prospectively is more complex. The difficulties have to do with the size of the sample of informants, usually the victims themselves (how to generalize from small samples); and obtaining reliable data (denominator and numerator) in war situations. The conclusion offered is that although a great deal of headway has been made and it has been possible to document actions inherent to the situation of conflict and differentiate them from deliberate extermination, there is still a long way to go in this regard.

In summary, this part of the book acknowledges that enormous methodological advances have been made by associating public health, human rights and health ethics, but major challenges still remain. Thus, while

there have been significant approximations between these disciplines, the differences are still considerable and conspicuous.

The third and final section of the book turns to policy – that is, to intervention properly speaking. It revisits the studies and issues examined in the preceding sections, either to discuss case examples or to examine the problems in critical aspects of intervention in such difficult situations.

Here the case of Brazil's AIDS Program is described and analyzed as a leading example of where the demands allied human rights and health very successfully. The study is well-written and generally a good account, even constructing quite a complete timeline of how Brazil's program to combat AIDS developed. However, the paucity of references to Brazilian authors and publications on the subject is unfortunate, because a great deal has been written. More careful consultation of that literature might perhaps have averted some historical errors and analytically incorrect statements.

For example, the Brazilian movements for health sector reform and for the rights of people with HIV/AIDS are parallel and connected, together with the feminist movement: they started in the mid-70s, but grew together and leveraged one another at specific political junctures. So in Brazil it was not the movement of people with HIV/AIDS or members of "risk groups" that drove discussion on human rights, as suggested by Gauri, Beyrer & Vaillancourt. The "Brazilian response" to the HIV/AIDS epidemic (or the "Brazilian model") was constructed on the basis of fundamental principles formulated either as a result of civil society action or government policy implementation. Actual implementation of concrete action did not really gain momentum at the national level until the new Constitution of 1988, which included the right to health as a citizens' right and the duty of the State. Those principles centered basically at the interface among social rights, human rights and citizenship, on a solidarity-based approach, which was the same approach advocated in turn by the health reform movement<sup>1</sup>.

The idea of solidarity was thus used as the key political concept to transform the prevalent discourse of stigma, prejudice and exclusion towards people with HIV/AIDS into a radically different discourse based on solidarity and inclusion.

Knowledge production by these three social movements was quite intense and fundamentally "militant": it was directed to producing evidence to inform policy-making and to transform the health service system, which it did by collecting and analyzing data on both access to the health system and the course of the epidemic, as well as studying the sexuality of people with HIV/AIDS, to demonstrate, among other things, that the socio-cultural determinants of sexuality and reproductive life are the same among ill and non-ill, etc. Lobbying by these social movements, supported by the knowledge they produced, prompted a dialogue with the State and a more politicized approach to the health issue, in turn driving technical reviews, the implementation of Brazil's

health sector reform and, concretely, introduction of the Unified Health System, SUS.

However, the action of these three movements differed significantly. Firstly, although the social and human rights issue was, and continues to be, the key rallying cry for all three movements, feminists and people with HIV/AIDS managed to organize, voice their demands and gain political strength by forging substantial links with civil society, particularly those who would be most directly affected by policy changes, the actual and potential service users – something the movement for health reform never managed to do. In addition, they also focused on the "broader" struggle, rather than restricting themselves specifically to healthcare issues, although these were an important aspect of their demands. As a result, in the 1990s, although conditions were unfavorable to implementation of the SUS and the movement for health sector reform was on the wane, the other two movements continued active. Pursuing their demands vigorously, they achieved gains in terms of services provided by the SUS, despite the difficulties and limitations imposed by the reform itself. It is this that has ensured the AIDS program continues "untouchable" and centralized, in addition to consuming enormous amounts of funding, although many other diseases in Brazil can be seen as deserving equal or higher priority. In any case, care for people with HIV/AIDS in Brazil can be said to be the most concrete demonstration that universalizing the health system and securing the State's commitment to public health is the most effective route to attaining equity in health.

In another rather interesting chapter of this section, Cohen, Kass & Beyrer raise the ethical issues associated with public health interventions and with research into human rights violations and damage to health.

Specifically as regards research, they point out that the traditional rules regulating health research ethics lack the necessary scope for this kind of research (Zimmerman & Watts; Yanhai & Xiaorong). They also underline that the HIV/AIDS pandemic marked an important watershed in this process. The funding destined for diagnosis, treatment and prevention was without precedent, both in volume and in coming from a variety of public and private sources. Also without precedent were the ethical and human rights problems raised both by the research and by the control methods recommended and employed by the various programs (Wolfe, Malinowska-Sempruch; Cohen, Kass & Beyrer).

Cohen *et al* argue that the tools of public health ethics and human rights are different, but complementary and should interact, both for evaluating public health interventions and for conducting research into human rights and damage to health. These two toolsets are regarded as differing mainly in the "legal integrity" of analyses of human rights violations; this has no equivalent in public health, where legal aspects do not have the same political force.

Using the example of AIDS, the authors argue that at least two mistaken notions tend to complicate the ap-

plication of human rights in public health. Firstly, they see a tendency for the rights of people with HIV/AIDS to be seen as part of “economic, social and cultural rights” (among which is the right to access health services), as opposed to “civil and political rights”, which are much stronger in legal terms. The second notion they consider wrong is the view that human rights issues set improper limits on the sovereignty of States, preventing them from acting in favor of the majority. The authors argue that it is exactly these problems that attest to the “indivisibility” of human rights, which have distinct dimensions that should not be considered separately. In addition, perhaps the most important goal of the ethical and legal tools for defending human rights is exactly to give a voice to minorities that are more vulnerable and often marginalized.

On the same line of reasoning, Cohen *et al* point to the differences between medical ethics and public health ethics, which although resting on the same underlying principles, differ on quite critical points, particularly because the former is directed to the individual and the second, to the collectivity. In the same way, they set out what they consider the main differences between public health ethics and human rights ethics: although public health ethics places emphasis on justice as a social goal and a social good, this is not grounded in solid laws that could make for greater power of enforcement and advocacy.

Lastly, in the book’s final chapter, Burkhalter highlights some advocacy strategies for achieving the right to health. Once again, the example is from the HIV/AIDS epidemic, but here the author examines the struggle of militants of the United States organization Physicians for Human Rights (PHR) to guarantee access to drugs for needy, ill populations in the world’s poorest countries. That battle involves important moral and ethical discussions, in addition to which each step forward raises new challenges. Here, any resemblance to events and processes experienced by health “militants” here in Brazil is no mere coincidence!

At this point, one important reservation is in order, which nonetheless does nothing to diminish the importance of this book.

The preface, introduction and several chapters always speak of the connection between “public health” and human rights, rather than – as we do here – between “health” and human rights. The authors start from a rather restricted, traditional conception of “public health”, very proper to the classical North American approach, apparently ignoring social epidemiology and the whole contemporary debate about health and health service equity and the social determinants of health, which has been underway for several decades and in which the right to health is seen as both a social right and a fundamental human right. Nor, in much the same way, does the book consider as inherent to this field the complex methodological resources resulting from the transdisciplinary nature of public health, which in Brazil has been conceptually recast as collective health.

As a result of this habit, the organizers commit some historical inaccuracies and minor analytical slips in affirming – incorrectly, in our view – that the human rights discussion paved the way for advocacy in favor of the needs, including health needs, of vulnerable groups. They explicitly recognize that it was only a few years ago that an organization like PHR, which has been operating since 1986, started to work with the right to health as a human right. In health, the discussion of principles based on ethical and moral values goes back to the 70s, underlying the whole debate over health and health service equity. The first and most consensual concept of health equity dates from 1991. In addition, in recent decades various countries’ constitutions have placed it on record, among other principles, that health is a citizens’ right and that health systems must be equitable.

Nonetheless, it is true – and in this the authors are quite right – that the mention of the right to health as a citizens’ right (and of equity in health systems) in various countries’ constitutions or in the laws of their contemporary health sector reforms is not enough to ensure that this will happen in practice. On the other hand, however, for at least thirty years many of us have been working hard for health systems to be universal, more just and equitable (here in Brazil and in several other countries in our region and outside it), advocating for the right to health as a fundamental human right. However, in Brazil too, despite the headway made by the health debate, the broader issue of human rights is still treated as parallel to and separate from health.

In summary, we have come a long way from back then, but certainly still have many paths to tread. Accordingly, the reinforcements brought to this debate by health-related human rights advocacy are extremely welcome and important, because extreme poverty and its consequences (unemployment, discrimination by gender, ethnicity, religion and so on), associated with the violence, corruption, brutality of governments and the laxity of laws, are far from ended in today’s world and are the mainstays of numerous ills that plague and devastate vast contingents of the world’s population. In that light, the need to construct robust empirical evidence is urgent.

To close, this book presents, with an impressive wealth of data and detail, the dramatic situations that researchers and activists work with. The writings aim to address clearly the crucial strategic points linking human rights and damage to health, always emphasizing the importance of research directed to supporting effective remedial intervention.

Generally speaking, the studies are denunciatory, partly because these dramatic situations are not remedied by research alone, but rather it is always clear that these populations are vulnerable in various different dimensions that are overlaid and cumulative, and the need is for more vigorous action, both by human rights advocacy and for the right to health.

A final, subtle challenge laid down by the authors has to do with the tradition of political neutrality reign-

ing in organizations that work with international health or with victim support activities in general around the world. According to Cris Beyrer, from the human rights standpoint, that attitude is unethical and scientifically unjustifiable – and, in our opinion, it is from the health standpoint too!

For the rest, this is a very well written book, with a wealth of information that makes it interesting reading, even for the layperson, which is rare in a technical text. So read this book! It is well worth it.

### Nota

1. This analysis can be found in: Galvão, J. (1997). As respostas das organizações não-governamentais brasileiras frente à epidemia de HIV/AIDS. In: Richard Parker (Org.) *Políticas, Instituições e AIDS: enfrentando a epidemia no Brasil*. Rio de Janeiro: Jorge Zahar/ABIA (69-108);

Parker, R. (1994), *A construção da solidariedade: AIDS, sexualidade e política no Brasil*. Rio de Janeiro: ABIA/IMS-UERJ/ Relume–Dumará. Paiva, V. (2003), Sem mágicas soluções: a prevenção do HIV e da AIDS como um processo de Emancipação Psicossocial. *Divulgação em Saúde para Debate*, (27):58-69. Parker, R. (2003), Construindo os alicerces para a resposta ao HIV/AIDS no Brasil: o desenvolvimento de políticas sobre o HIV/AIDS, 1982-1996. *Divulgação em Saúde para Debate*, (27):8-49. A comparative discussion of these two movements was presented by Celia Almeida at the round table “The Health Reform Movement: a critical view”, during the 6th National Congress of the UNIDA Network – 20 years of partnerships in health and education – from 2-5 July 2005, in Belo Horizonte, Minas Gerais, Brazil. A report on that thinking was published in the congress proceedings. 