A long way from there to here: human rights approaches to HIV/AIDS in a local setting

Although global and national strategies to promote a human rights–based approach to HIV/AIDS have been in place for many years, these strategies appear to have had little impact at the local level, where human rights violations are commonplace. In this article, Peris Jones and Farhana Zuberi summarize findings from a recently completed research project, the Tswelopele study, in South Africa.[1] The study documented human rights violations in three areas: privacy and disclosure; informed consent and HIV testing; and access to health-care services. The article describes these violations and explores why discrimination still occurs at the local level. The authors conclude that remedial action is required, targeting the persons and institutions that shape attitudes and beliefs, including churches, workplaces, schools, and the media; and that this action needs to be complemented by wider public education, activism at hospitals and in the courts and, more generally, fulfilment of socio-economic rights.

Introduction

The plethora of legislation, policies, campaigns, and case law in recent years points to the giant steps taken in promoting a rights-based approach to HIV/AIDS. The international community has been involved in various initiatives such as the International Guidelines on HIV/AIDS and Human Rights[2] and the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS.[3] Such developments are obviously integral to coalescing a rights-based platform to confront the epidemic.

However, as Mark Heywood points out, "despite the evolution of the human rights paradigm into explanatory notes, guidelines, and best practices, human rights violations continue."[4] The good ship "human rights protection" would once again appear to be foundering on the rocks of non-implementation. Plotting the course of its global voyage from UNAIDS or the United Nations Office of the High Commissioner for Human Rights (UN OHCHR) is certainly an important endeavour. But another is surely to ask whether the human rights "project," if we can call it that, sufficiently engages the varied national and local obstacles blocking the path of implementation in the context of HIV/AIDS.

Not least, while much work has been done and documented at global and national levels, there is scant information on the impact of the human rights approach on local communities. After all, according to Peter Piot, Executive Director of UNAIDS: "Unlocking the power of community is the key to making the transition from pilot to full-scale responses. Africa is changing gears, and it is communities who are sitting in the driver's seat. Now is the time for the global and the local to meet." The Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa (AMICAALL), quoting Mr Piot above, assert that "national government officials may be too far away to hear the voice of ordinary citizens."[5]

There is, of course, danger in uncritically singing the virtues of the local level. In development theory and practice the "local" is often portrayed as some kind of benign, homogenous, and apolitical container, seemingly detached from global and national dynamics, and ripe for all kinds of outside interventions.[6] Nonetheless, the local scale remains relevant to human rights for at least two reasons. First, this is the terrain where the majority of people living with HIV or AIDS (PLHAs) encounter daily stigma, discrimination, and barriers to accessing health services. Second, extending the benefits of human rights protection does not occur on the head of a pin: in other words, it has to be located somewhere, and consequently must confront localized obstacles to implementation.

HIV/AIDS and human rights in South Africa

At the national level, South Africa has responded to human rights challenges in a variety of ways. South Africa is party to a range of international and regional human rights instruments.[7] While the majority of these instruments do not specifically mention HIV/AIDS, several provisions are applicable to the situation of PLHAs.

The Constitution of the Republic of South Africa, Act No 108 of 1996, also lists several justiciable socio-economic and civil and political rights, such as: equality; human dignity; freedom and security of the person; privacy; freedom of expression; freedom of association; freedom of movement and residence; freedom of trade, occupation, and profession; right to a healthy environment; right of access to housing, health care, food, water, and social security; and right of access to information. The Department of Health, in its *HIV/AIDS/STD Strategic Plan for South Africa 2000-2005*, has also recognized the importance of human rights in combating the spread of HIV/AIDS, and has included human rights and legal issues as one of the five key priority issues of the Plan.

> One of the objectives of the study was to determine if local communities have taken ownership of human rights, and are able to access and enforce their rights.

One particular motivating force for the Tswelopele study was to identify the relevance of these human rights provisions in a specific community and area that can be classified as semi-urban and rural. One of the objectives of the study was to illustrate the extent to which the human rights approach has been localized; in other words, to determine if local communities have taken ownership of human rights, and are able to access and enforce their rights. The study also asked whether the ideals contained in the International Guidelines and the Constitution have permeated to the local community level.

Hammanskraal and Temba

The study was undertaken in Hammanskraal and Temba, which under the demarcation of 2000 fall within the Tshwane (Pretoria) Municipality. The area also crosses provincial boundaries, creating a situation of overlap for various services, including health and education. Thus, both the Tshwane Municipality (Gauteng Province) and the Moretele Local Municipality (North-West Province) are involved in service delivery. While there is an elected local council, there are also tribal authorities that are still prominent in the area. The population[8] of the area is 80,573 (9,664 in Hammanskraal and 70,909 in Temba). The majority of the population is African,[9] with low levels of education, employment, and income. The HIV/AIDS prevalence rate is estimated to be in line with the rest of the country at 21.5 percent.[10]

There are approximately 24 governmental and community-based organizations providing a range of HIV/AIDS services (excluding research) in the area. There are 26 primary health clinics and two mobile health clinics; six clinics offer nevirapine as part of the government's prevention of mother-to-child transmission (PMTCT) program, and 16 clinics offer voluntary counselling and testing (VCT) services. Jubilee is the public hospital for the locality; it offers VCT and PMTCT services, but has not been selected as a site for the government's antiretroviral treatment (ARV) rollout. Despite the number of services available, and the fact that two provinces and two municipalities are involved, effective service delivery is very limited. In general, resources are clustered in Temba and although there have been HIV/AIDS initiatives within the community there is little or no coordination of these activities.

Key findings from the research

The study was based upon data collected between February and May 2004. The primary data-collection methodology was focus group discussions with PLHAs from the local hospice, and non-PLHAs such as members of social clubs, youth groups, local government councillors, health-care workers, and volunteers at AIDS service organizations (ASOs). This was supplemented by key informant interviews and with observations undertaken in health-care settings such as hospitals, clinics, and other government service delivery points.[11] For the purposes of the analysis, people were classified into two categories: (1) PLHA groups, which comprised those people who were attending the local hospice and openly living with HIV or AIDS; and (2) non-PLHA groups, which comprised everyone else.

A particular concern of the project was to investigate stigma and its construction as the basis of discrimination. Stigma was revealed as a complex and dynamic phenomenon embedded in community and gender relations, with gossip acting as an important conduit. The major human rights violations stemming from stigmatization were identified and are described below.

Privacy and disclosure

The issue of privacy was a major concern for PLHAs, who indicated the importance of deciding how, when, and to whom to disclose one's status. PLHAs recounted stories of having status disclosed without consent, and how this impacted on them. In many cases, the person who disclosed without consent was a health-care worker from a clinic or hospital. While this was deemed totally unacceptable and often traumatic, PLHAs stated that they had nowhere to turn to complain or for redress. When they turned to the police, they were not taken seriously; complaints to the health-care institution also amounted to nothing. There was overall agreement that if only one could afford a lawyer, then one could see justice done.

The non-PLHA groups also mentioned the importance of privacy and disclosure, with most people recognizing the importance of keeping one's status private. Linkages were made between stigma and disclosure: "If there was no stigma against people who are HIV positive, people would easily disclose their status. People want to disclose but they are afraid of the reaction from their community and how the community will treat them once it knows their status." However, non-PLHAs thought it was precisely because of the lack of disclosure that PLHAs were vilified in the community. They held the view that it was necessary for people to disclose in order for HIV/AIDS to be demystified and treated just like any other disease. As non-PLHAs saw it, privacy had led to the creation of HIV/AIDS as "special." Some non-PLHAs saw privacy as very problematic, stating that the focus on privacy was leading to the spread of the disease.

Volunteers at ASOs and health-care workers also saw privacy and confidentiality as problematic because confidentiality was seen as limiting the extent of assistance they could provide to PLHAs. They argued that the inability to disclose the status of a person to colleagues and others such as family members impeded patients from receiving the best care available. For health-care workers this was more related to the need to protect the family member/caregiver from possible infection, rather than to ensure that the patient was given the best possible treatment at home.

> "If there was no stigma against people who are HIV positive, people would easily disclose their status."

Informed consent and HIV testing

Most people, including health-care workers and PLHAs, shared stories of being tested without having given consent, and without pre- and post-test counselling. One respondent recounted being told by a health-care worker, "You are going to die, you have the virus." Respondents agreed that testing was a traumatic experience and that it took a great deal of courage to finally have a test. Most women, including nurses, had been tested during pregnancy, often years ago, and had not been retested since.

Observation undertaken at the clinics illustrated that there was little in the way of confidentiality and privacy when going for an HIV test. Most clinics did what they could with limited resources; often the counselling took place in a room that doubled as a medicines storeroom, with people coming in and out. When the clinic was busy, people who came in for tests could be turned away due to lack of personnel to do the counselling and testing. The need for individual pre- and post- test counselling was seen as unrealistic in the already under-resourced and overburdened public health system.

HIV testing was seen to be on the increase because of the access to disability grants, and both health-care workers and non-PLHAs regarded this with some cynicism.[12] The non-PLHA community groups expressed worry about welfare abuse by people claiming to be living with HIV or AIDS. There was a perception that unscrupulous doctors were signing the requisite forms for healthy individuals, making them eligible for grants.

When challenged on how to deal with this issue, one community respondent indicated that there was a need to retest all PLHAs in the area, even if this involved locking them in a stadium and forcing them to retest – in other words, the need to curb welfare fraud would override the need for informed consent. Forced testing also came up in one focus group and key informant interview relating to the need to test pregnant women in an effort to protect the unborn child from infection.

Finally, there was a broader discussion about what constituted informed consent, and whether it was possible to get informed consent from someone who was sick.

Access to health-care services

Both PLHAs and non-PLHAs complained about the treatment they had received at the hospital and clinics in the area. Non-PLHA groups complained about the waiting period, and about the fact that there were no doctors available, that the drugs were never in the pharmacy, and that the level of service at Jubilee was less than acceptable. As one woman said about having to go to Jubilee: "I won't go there, I will stay away." They alleged that it was useless to complain since the suggestion boxes at the institutions were opened and suggestions were reviewed by the supervisors, who simply destroyed all complaints.

Access to health care and treatment was a major concern for all the PLHA groups. PLHAs regarded their ill treatment by health-care workers as directly related to their HIV status. The majority of the PLHAs indicated that they would not go to the hospital, even when they were very ill, and would prefer the treatment they received at home, which was far from adequate, to the treatment they received at the hands of health-care workers.

Most PLHAs were able to recount stories of being forced to wait to use the bathroom or being told to "go yourself"; of staff disclosing status and gossiping about patients in front of others; of staff passing "funny remarks"; of staff refusing treatment or giving the wrong medication; of staff violating a right to privacy by identifying HIV-positive patients with a special diagnosis code (Code 279) written on charts; and of HIV patients being segregated in specific wards.

In one focus group, it was stated: "Sometimes when you are taken to the hospital and they [nursing sisters] can see that you are very ill, they don't attend to you, they just say take this person there, there is nothing we can do for him. They don't want to understand that this person is in pain and needs an urgent help, therefore they must give him the special attention; they just become harsh on him." Nurses were seen to have "an attitude," especially against those with HIV or AIDS.

Nurses, on the other hand, vehemently denied that they treat PLHAs differently and that people with HIV were segregated in specific wards.[13] They suggested that people had unrealistic expectations of them and that no matter what they did, it was never seen as good enough. Nurses complained of being overworked, and being affected psychologically by the number of people who were dying, and whom they dealt with daily. They also complained about visitors coming to "snoop around" rather than to visit patients.

Nurses blamed families for treating people with HIV badly and cited examples of family members dumping patients in the hospital and not coming to collect discharged patients; and patients being admitted when they were dirty and with bedsores, showing that they were not cared for at home. Nursing sisters themselves felt stigmatized: "So we like our jobs even though the community labels and stigmatizes us and even God knows we are doing our best. We wake up in the morning knowing what kind of patients we will see but we still go to work and do our best."

> Many people saw human rights as a problem rather than as a means of empowerment.

Is a human rights approach at the community level sufficient?

In Hammanskraal and Temba, it was clear that human rights violations continued against PLHAs despite the human rights protections espoused in international and national legislation and policies. This could arguably be attributed to a number of factors, including the following:

- Most people did not know about human rights. They had not read or been exposed to the Bill of Rights.
- It is difficult to make rights real. Is this even possible in an environment of poverty and unemployment?
- The community was not aware of how to enforce the rights that had been violated, and there were few if any organizations in the community that could provide assistance.
- Many people saw human rights as a problem rather than as a means of empowerment.

These factors will be discussed briefly in turn.

Lack of information

When asked about the Constitution, the majority of people interviewed were able only to recognize it, but not give any details about what was in it. Questions were met with silence or vague answers about rights. Thus, there had been little in terms of dissemination of the practical content of rights at the community level. This impacted on people's ability to claim their rights – if a person does not know what a human right is in a practical sense, he or she will not be in a position to recognize a violation and claim redress or enforcement of the right.

Other laws that deal with non-discrimination, such as the Employment Equity Act, No 55 of 1998, were also not known to the community.

Making rights real

One respondent said, "I believe if people can know their rights, things will be better. I sometimes believe it is useless to know your rights if you do not know how to exercise them."

Many people indicated that it was not possible for them to exercise their rights. They felt helpless and disempowered in trying to access rights such as the right to health-care services, giving examples of complaints falling on deaf ears, with no changes ever being made. For example, people complained about the lack of local government delivery in the area with respect to water, electricity, and other basic services; importantly, they felt that they had no recourse, or anywhere to complain to make a difference.

It was suggested that people in the community could not make rights real because they prioritized other issues such as poverty, and human rights were seen as secondary, or almost a "luxury" item. The focus on work and simply making a living meant that human rights played a less significant role in life. A teacher in the community reinforced this sentiment by indicating that, although she was discriminated against after disclosing her status at school, she did not have any time to deal with the violations because she was busy working, as she had a family to support.

Another reason given for the failure to access human rights was the link between stigma and discrimination. The link was recognized in many groups, and fear of stigmatization was seen as one of the primary reasons why people did not speak out and try to enforce their rights in the community.

Few organizations to assist with enforcement

Even when violations occurred and were recognized, most community members did not know where to go for assistance. The stakeholders that were mentioned – such as the police, traditional leaders, and local government – were seen as being totally unable or unwilling to help. Many people interviewed could not name any organizations in the area that could be of assistance. People mentioned having to go from one place to another trying to obtain help. For example, in trying to deal with family violence, women were usually sent to the police and then the courts, and often did not have sufficient funds for transport. Other people mentioned that they do not know where to go to report abuses such as unauthorized disclosure by health-care workers and doctors.

Institutions such as the Department of Labour and the South African Human Rights Commission were mentioned in very vague terms. People who were interviewed were not able to give details of whom to contact and the mandate of such institutions. While municipal officials indicated that it was possible for people to come to them for assistance, most people felt that the municipality had little to offer.

One of the focus groups of PLHAs mentioned that large AIDS organizations such as the National Association of People Living with AIDS (NAPWA) and the Treatment Action Campaign (TAC) should be able to provide assistance with problems, but said that they did not play a role in Hammanskraal. The large organizations were treated with some suspicion, and were seen to be visible only when they needed support for campaigns. It was actually difficult to find any organizations in the community that dealt specifically with human rights violations. Those that supposedly did were not accessible even to the researchers during the course of the study.

> There is a disjuncture between thinking at global and local levels that will obviously need to be addressed for a rights-based approach to be effective.

Repeated attempts were made to contact both the TAC and NAPWA to meet with them and discuss their involvement in the area, but these proved unsuccessful. Many PLHAs had paid for membership in NAPWA, but were not clear about the services it offered or even whether or not there was a branch in Hammanskraal or Temba. During the research period, there was a planned relaunch of NAPWA. While several people waited at a meeting venue for several hours, NAPWA representatives did not arrive. Thus, it appears that the TAC and NAPWA, the largest national AIDS organizations in the country, played little (if any) role in the area.

Human rights: solution or problem?

Many people saw human rights as a problem rather than as a solution. The police saw the Bill of Rights as preventing them from doing their job properly, and argued that community education campaigns with respect to rights in the Constitution did not include information about accompanying responsibilities. The traditional leader interviewed claimed that human rights were eroding the traditional way of life in the villages, and causing the breakdown of traditional values. PLHAs alleged that access to information about sex made young people more likely to engage in sexual behaviour, thus leading to a spread of HIV. Nurses thought that access to child-care grants made young women fall pregnant, which led to the spread of HIV. As discussed above, many people suggested that confidentiality and informed consent were unimportant, and that non-consensual HIV testing should take place.

It is important to pay attention to these issues since they display a disjuncture between thinking at global and local levels and will obviously need to be addressed for a rights-based approach to be effective.

Conclusion

The research findings suggest that although global and national strategies have been in place for many years, the rights-based approach has made little difference to the lives of people in the community. Additional findings on labelling, blame, gossip, and social exclusion of PLHAs, or those suspected to be HIV-positive, showed an apparent disjuncture between rights and reality. While some people might know what their rights are and how to exercise them – including the rights of the infected or affected – the lived reality of PLHAs and the communities from which they come may be quite different.

People are still subject to human rights violations and have difficulty making their rights real. Importantly, people often believe that human rights are a burden or a luxury, and only relevant to those with enough money to enforce them. Much still needs to be done to ensure that people can understand and benefit from a human rights approach. Taking human rights into an effective AIDS response means intervening at the level of community and personal gossip, at the places where perceptions are formed; this could mean targeting persons and institutions that shape attitudes and beliefs, including churches, workplaces, schools, and the media. This needs to be supported by formal action – at hospitals, through the courts, paralegal training, and wide public education – in an effort to find ways in which a different social construction can be developed to make people trust the law and appreciate that rights can work for the wider social good.

Above all, if a human rights discourse is to be relevant in a context where local residents face severe poverty and unemployment, a critical dialogue is required between human rights and socio-economic needs. The justiciability of socio-economic rights may be rapidly gaining ground at a national level in South Africa, but it still requires connection to local-level struggles and especially implementation in areas like Hammanskraal for it be to regarded as relevant locally.

– Peris Jones and Farhana Zuberi

Dr Peris Jones is a researcher with the South Africa Programme, Norwegian Centre for Human Rights. He can be reached at peris.jones@nchr.uio.no. Farhana Zuberi is a human rights lawyer at the Centre for the Study of AIDS, University of Pretoria, South Africa. She can be reached at zuberi@mweb.co.za. The authors would like to thank Solomon Shirinda, Hammanskraal Satellite Campus Coordinator for the Centre for the Study of AIDS, for his invaluable input and assistance during the course of the Tswelopele study.

---

[1] HIV/AIDS stigma and human rights: A localised investigation of Hammanskraal communities. A report of the Tswelopele Research project of the Centre for the Study of AIDS. Available via www.csa.za.org.

[2] Accessible via www.ohchr.org.

[3] Accessible via www.unaids.org.

[4] M Heywood. Human Rights and HIV/AIDS in the context of 3 by 5: time for new directions? *Canadian HIV/AIDS Policy and Law Review* 2004; 9(2): 1, 7-13.

[5] AMICAALL recognizes the need for action at the local level, and the vital role that is to be played by municipalities. For more information, refer to the AMICAALL website at www.amicaall.org.

[6] G Mohan, K Stokke. Participatory development and empowerment: the dangers of localism. *Third World Quarterly* 2000; 21(2): 247-268.

[7] A complete list of international instruments, current as of 1 October 2004, is available from the OHCHR website at www.ohchr.org/english/bodies/docs/RatificationStatus.pdf. The list of ratifications of regional instruments is available at the AU website at www.africa-union.org/home/Welcome.htm.

[8] Demographic information is from the 2001census, available at the Demarcation Board website at www.demarcation.org.za.

[9] During apartheid, populations in South Africa were classified as White, Indian, Coloured, and African. For ease of classification, the government has retained this system.

[10] UNAIDS. 2004 Report on the Global AIDS Epidemic. Available via www.unaids.org.

[11] For information on focus groups, key informants interviews, and the observations undertaken, see Appendix 1 of the Tswelopele report (supra, note 1).

[12] On the other hand, access to disability grants was a vital issue, raised in all PLHA focus groups, and seen to be necessary for livelihood as PLHAs perceived that they had even less access to employment and services than others in the area.

[13] The issue of segregation in specific wards in Jubilee was one that was raised in many groups. People from the community had heard of specific wards where HIV-positive patients were admitted. However, the alleged segregation was denied by the nurses, who argued that, no matter which ward an HIV-positive person was admitted into, it was seen by the community as a ward for HIV-positive persons simply due to ignorance.