

Testing, trials and re-thinking human rights: Reflections from the HIV pandemic

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AUSTRALASIAN SOCIETY FOR HIV MEDICINE INC.

SCHOOL OF PUBLIC HEALTH AND COMMUNITY MEDICINE, UNIVERSITY OF NSW

NATIONAL CENTRE IN HIV SOCIAL RESEARCH, UNIVERSITY OF NSW

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REFLECTIONS FROM THE HIV PANDEMIC

Editors Niamh Stephenson, Cammi Webb, Marina Carman



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Introduction

BY NIAMH STEPHENSON

Nearly a decade ago, the British Medical Journal published an editorial which described how the imperative to work within a human rights framework would become increasingly evident as health workers and researchers recognised and tried to tackle the social determinants of health.¹ This monograph outlines some contemporary explorations of the promises and challenges of approaching HIV through the framework of human rights.

As both Susan Kippax and David Buchanan note, the difference between countries' successes and failures in tackling HIV epidemics can be broadly understood in terms of human rights. Countries which have failed to tackle HIV are often marked by conflict, a history of colonisation and high levels of stigma and discrimination against HIV-positive people, or people suspected of being positive. Those which have been more successful have introduced policies and legislation which work towards enabling people's agency, and work against the proliferation of discriminatory social practices.

International human rights are about more than diagnosis of vulnerability and the admonishment of neglectful, or actively discriminatory, states. The promise of the human rights framework is that it provides a way of moving forward on health inequalities; this approach is fundamentally aspirational, without being unrealistic. The inability of many states to provide adequate resources for the fulfilment of all human rights is acknowledged in the principle of 'progressive realisation' of the right to the highest attainable standard of physical and mental health. This principle obligates all states to continue to move towards the goal of fulfilment, and it requires wealthier countries to contribute to international efforts to further human rights.²

In order to consider the specific challenges of such commitments for those involved in preventing and managing HIV, we invited the contributors to this volume to discuss human rights in HIV policy and research. Initially contributors were invited to participate in a seminar on World AIDS Day 2004, co-organised by the School of Public Health and Community Medicine (SPHCM) and the National Centre in HIV Social Research (NCHSR) at the University of New South Wales. This monograph developed out of presentations at this seminar.

For those working in HIV, focusing on human rights at this point in time seems particularly important for a number of reasons. One is concern over international aid for HIV prevention being tied to moral agendas, leading to the proliferation of over-simplistic and potentially lethal policies. This raises a related concern: that what we are witnessing is a paternalistic recognition of people's vulnerability, in place of moves to actively recognise

and promote the agency of those most affected by HIV. Another reason for employing a human rights framework is that the trial and development of vaccines and HIV treatments challenges us to identify ways to interrupt processes through which research collaborators are reduced to consumers – or worse, reduced to people and states without the sufficient means to be consumers. In addition, the World Health Organization's campaign to get three million people on treatments by 2005 (the '3 x 5' initiative) is raising new concerns about the use of testing technologies.

What follows is a set of explorations along two distinct trajectories. Some contributors invoke human rights as a means for tackling injustices in HIV prevention, treatment and research, whilst others specifically examine the tensions inherent within a human rights framework.

Susan Kippax writes about the human rights challenges being raised by current shifts towards individual (or couples') testing in the context of the '3 x 5' initiative. This is an important issue, as over-emphasising testing shores up ineffective individualistic approaches to HIV prevention and risks fuelling, rather than confronting, stigma and HIV-related discrimination. Using testing as a means of HIV prevention risks ignoring what we have learnt about effective prevention. Firstly, HIV prevention efforts are most effective when governments are actively involved in and supportive of collective efforts to openly discuss and to transform social and sexual practices. Secondly, effective prevention takes the form of education which promotes people's agency. On this topic, David Buchanan questions moves towards 'routine testing' in the absence of legislation which protects the human rights of those who are at risk because of their HIV status. If testing is undertaken in a way which reduces people's agency, how can it then contribute to the empowerment of people – empowerment which will be vital to subsequent prevention efforts? Such moves are questionable in the absence of adequate human rights.

In part, a human rights framework works to promote health by fuelling continual engagement with questions of empowerment, and this is its importance for those working in vaccine and treatment development.

Bridget Haire's paper foregrounds the irony of the increasing visibility of women as vulnerable victims of infection, compared with women's relative invisibility in biomedical research. She proposes a vaccine trial program which – instead of sidelining women – would allow for the specific development of drugs suitable for women's bodies and needs. In his paper, John Kaldor returns to the ethical dilemmas involved in vaccine trials – the problems of choice and informed consent, of behaviour change potentially increasing a participant's likelihood of exposure to HIV, and of the nature and limitations of researchers' responsibility to provide treatment for those who seroconvert whilst participating in trials.

Addressing the broader challenges inherent in adopting a human rights approach, Elizabeth Reid focuses on the importance of realising the aspirational dimension of human rights. She argues against an exclusive legalistic framing of human rights, on the grounds that it risks emphasising transgressions, as opposed to promoting understanding of how injustices are confronted, and rights are instated and upheld. Change needs to occur, not only at the level of legislation, but in social institutions and social relations.

Reid illustrates the importance of focusing on the micro-practices involved in social relations as she recounts how sustained community conversations have enabled communities to initiate behaviour change and tackle gender inequalities through creating inclusive spaces where collective responsibility for HIV is cultivated. Also exploring the tensions within the discourse of human rights, Michael Burke's paper cautions against limiting the potential of an international human rights framework by invoking culturally inappropriate notions of rights and by overlooking the role of 'coalitions, conversations and courage' to strengthen community action.

Together, the contributors to this volume powerfully demonstrate the centrality of human rights in contemporary problems pertaining to HIV prevention, the development of vaccines and more effective treatments, as well as access to treatment and use of testing technologies.

Whilst the authors' work is evident in what follows, that of many others involved in the production of this monograph requires specific acknowledgement. Edward Reis, Cammi Webb, Marina Carman and Vicky Fisher at the Australasian Society for HIV Medicine brought this work from a series of seminar papers to publication. The support of Susan Kippax at the NCHSR and Anthony Zwi at SPCHM, and the assistance of Jacqui Miller at the SHPCM, were vital in the planning and organisation of the original seminar.

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A public health dilemma: the vexed question of Voluntary Counselling and Testing

BY SUSAN KIPPAX

This paper focuses on recent moves in the international policies of bodies such as the World Health Organization and UNAIDS concerning the roll-out of HIV treatments and the related roll-out of testing, in the form of provider-initiated testing. In particular, it focuses on the impact of such moves on stigma and discrimination and on effective prevention programmes.

INTRODUCTION

AIDS, or acquired immune deficiency syndrome, is caused by a retrovirus – the human immunodeficiency virus (HIV) – identified in 1984. Twenty years later it is estimated that over 20 million people have died of AIDS and 40 million people are living with HIV, with 95% living in developing countries. The world is facing a global pandemic, a pandemic marked by inequalities of class, gender, race and sexual preference.

As we all know, HIV, a blood-borne virus, is most commonly transmitted by sexual practice, particularly penetrative intercourse (vaginal and anal) with an HIV-infected person. It is also transmitted by the sharing of HIV-contaminated needles and syringes, from an HIV-positive mother to child during birth and breast feeding, and via the transfusion of infected blood and blood products. The population most affected by HIV comprises young men and women of reproductive age.

There is, at present, no effective prophylactic vaccine for HIV/AIDS, nor an effective microbicide. There is also no cure for HIV; although, since 1996, treatments have been developed, in the form of antiretroviral therapy (ART) and, more recently, fusion inhibitors that block HIV from entering the body's immune cells. These therapies effectively slow (but do not stop) the progression from HIV to AIDS to death. Mother-to-child transmission can be almost completely eradicated using these drugs. And there have been further moves to use ART as post-exposure and pre-exposure prophylaxis.

In the developed world, where most people living with HIV have access to these expensive therapies, there has been an 80% fall in deaths related to AIDS. If treatment uptake is extensive then these therapies may also act in a preventive fashion by lowering the population viral load.

HIV can be prevented by changes in sexual and drug use practices – abstinence, and the use of condoms, clean needles and syringes. In the absence of an effective prophylactic vaccine and an effective microbicide, these behavioural changes are the main prevention tools at our disposal. HIV prevention works particularly where: governments acknowledge HIV; are committed to

prevention; support social movements by funding affected communities to work with public health and social science to combat HIV transmission; and provide treatments, care and support for those living with HIV and AIDS. In the absence of these factors, prevention efforts falter. Prevention is also undermined by stigma and discrimination.

Because of its association with sexual behaviour and drug use, HIV is highly stigmatised. Where the patterning of HIV infection indicates a 'local' as opposed to a 'generalised' epidemic, gay men, sex workers and injection drug users are positioned as 'risk groups', and HIV positioned as the disease of 'the Other'.

In countries such as those in southern Africa where the epidemic is generalised and prevalence rates reach 25 to 30 per cent in the adult population, women with HIV are often stigmatised as promiscuous. Moral agendas in many countries have fed into such stigma and thwarted prevention efforts; some governments claim that sex education promotes sexual activity among the young; others, particularly those with religious affiliations, promote monogamy, which is now acknowledged to be a risk factor – at least for married women; still others condemn needle and syringe programs as promoting illegal behaviours.

While no one is certain about why some countries have a higher prevalence than others, or why some countries have managed to radically reduce prevalence levels, two patterns are slowly emerging.

The first pattern is that successful responses to HIV are dependent on a human rights/modern public health approach that empowers civil society, gives it a voice and ensures that communities have a secure place within the national dialogue. In general, the response has succeeded where this had been adopted – in the developed world and also, in some instances, in the developing world. Such an approach entails communities encouraging and supporting individuals, understood as rational agents, to reduce harm to themselves and others, and giving people access to treatment. The example, of course, with which we are most familiar has been the success in Australia – where AIDS Councils, funded by governments, have given

their communities a voice, have supported them to work with public health and social science to educate themselves, and have provided treatments for all those with HIV.

Voluntary counselling and testing (VCT) played a part in this Australian response – and continues to do so – although most AIDS Councils did not endorse testing until some of the early treatments were made available. At present a very large proportion of the gay community, and indeed most of those at risk in Australia, are regularly tested. Furthermore, among those who are infected, treatment uptake is good; most in need of treatment are on therapy.

Focusing on apparent failure rather than success, the second pattern that is emerging is that economic and civil disruption – in the form of colonisation, conflict or war – increases the vulnerability of countries to HIV. Not only have prevention efforts been thwarted by gender inequalities, poverty, and uncertainty, but the prospects of treatment for all continue to fade even given the recent moves for treatment access. The Global Fund to Fight AIDS, Tuberculosis and Malaria has committed to distribute funds to countries for, among other things, the purchase of antiretrovirals, and the World Health Organization's '3 x 5' initiative aims to provide ART to three million people by the end of 2005.

These initiatives – welcomed by many, if not all – have placed an additional burden on the developing world, the burden to test their populations. They also carry with them the risk of down-playing prevention or relegating it to the clinic. However, these initiatives have themselves been thwarted by stigma and discrimination; people are not coming forward for testing and the estimated millions who are unaware they have HIV are, of course, not being treated.

Policy moves of concern here relate to testing – and the move to introduce 'routine offers of testing' or provider-initiated testing in countries with high HIV prevalence. VCT plays a central role here – but a different one from that described above in the Australian example.

As I turn to illustrate this move, I want to distinguish the role of the clinic in ordinary everyday voluntary counselling and testing, and care and support (as was and is the case in Australia), from the role of the clinic where VCT (written large) is positioned as a major, or indeed the major, response to HIV – both for treatment roll-out and prevention.

In the context of the success of treatments (and, I believe, growing conservatism), there is a move that is gathering momentum to position VCT as the major response to HIV and the major tool for prevention. While I have no quarrel with using VCT as a vehicle for reinforcing prevention, there is mounting evidence that the inclusion of HIV prevention education and advice within VCT is only partially effective. Furthermore, there is evidence that in many countries in the developing world, prevention in the context of VCT is creating personal and social problems for a substantial proportion of individual clients/patients. Unless VCT is conducted with some understanding of the social and cultural lives of the people

who avail themselves of it, the outcomes may include the disempowerment of its recipients and increased social stigma and discrimination.

A number of studies have begun to look at the negative as well as the positive effects of testing. For example, in 2000, *The Lancet* published a paper conducted by The Voluntary HIV-1 Counselling and Testing Efficacy Study Group.¹ This paper described the outcomes of a study in Kenya, Tanzania and Trinidad of over 3120 individuals and 586 couples who were randomly assigned to VCT or basic health information. A meta-analysis has been done of published data on VCT efforts (incorporating the findings from this study, and others in the US, Africa and Europe)². This indicates that although there is some evidence that there is an under-reporting of unprotected sex³, VCT appears to provide an effective means of secondary prevention (i.e. decreasing the likelihood of infected individuals infecting others), but does not appear effective in primary prevention, as uninfected individuals did not reduce their risk behaviour.

A number of other studies (including some of the above) point to some very worrying problems and complexities associated with VCT – particularly in relation to its role in prevention. For example, there are problems for women in terms of disclosure of HIV status⁴, fear of stigma associated with an HIV-positive result⁵, and a number of negative life events following testing⁶.

Maman et al.⁷ found that the most salient barriers to HIV testing and serostatus disclosure among women they surveyed in Dar es Salaam, Tanzania, were fear of partners' reaction, decision-making and communication patterns between partners, and male partners' attitudes towards HIV testing. Burke's⁸ findings in his study indicate that women have some reason to be fearful of testing and that communication patterns between men and women in rural Tanzania undermine disclosure of test status by the female partner and work against discussion of sexual transmission of HIV between the male and female sexual partners.

The work of Grinstead et al.⁹ quantifies these fears and problems – as negative life events. Their study in Trinidad, Tanzania and Kenya found that for individuals, positive serostatus was associated with the break-up of marriage and being neglected or disowned by family. Serodiscordant couples with an HIV-positive woman were most likely to report the break-up of a marriage (20% versus 0-7% for other groups), and the break-up of a sexual relationship (45% versus 22-38% for other groups). Physical abuse was also experienced by HIV-positive women in serodiscordant relationships (13%), and was higher in HIV-positive seroconcordant relationships (12%) versus (0-3% for other groups). There were some positive life events following VCT, mainly in the form of increased emotional support for HIV-positive individuals and couples. Kalichman and Simbayi¹⁰ note that stigma is likely to pose considerable barriers to seeking VCT or testing in South Africa, and, quite possibly, elsewhere in Africa, if not further afield.

Not surprisingly, given these outcomes, general population readiness for VCT in some countries, e.g. Zambia, is very low¹¹. In a population-based survey of Zambians, Fylkesnes et al. reported that while the proportion

of people indicating initial willingness to be HIV tested and counselled was 37%, only 3.7% of these came forward for testing, and of these just under half returned for their test result (overall less than 200 of the 4812 people surveyed).

There are other issues that have been noted by researchers¹². These include increased stigma and discrimination – at least in the short term. This is related to negative social and personal problems – fear of infection and the impact on sexual relationships/marriage, and disowning and neglect by families. Many who do take up VCT refrain from disclosing their status because of these anxieties and very real fears.

Furthermore, because VCT takes place in the clinic, people are positioned as patients – as passive. This is disempowering in the sense that it is 'top down' and pays little if any attention to the ways in which the VCT messages are interpreted and understood by those who receive the message. VCT has a tendency to make the patient a passive recipient of information and advice; not a characteristic of good effective education.

VCT is individualistic (at its best it talks to couples) and hence it makes little, if any, impact on prevailing normative understandings of sex and risk. Knowledge is privatised. Because VCT is individually focused, it reinforces notions of individual responsibility and hence may feed blame and shame, and more generally, stigma and discrimination.

VCT as prevention will mean that the people most likely to receive HIV information are those who for a variety of reasons come to get tested for HIV – many of whom are already HIV positive. What will those who are HIV-negative do? What will be their understandings, their assumptions about safety?

VCT will mean that those who do not believe themselves to be at risk – or those who deny their risk – will not come forward. They will miss out on the HIV-prevention education. It will mean that the young, those at school, those who live outside urban areas where VCT facilities exist, are likely to receive little by way of informed education and health promotion.

Even more importantly – perhaps most importantly – rolling prevention into VCT (or extending VCT so as to make it a major prevention tool) will give governments the excuse to draw back from HIV, the excuse not to have to deal with and face the complexities of talking about sex and drugs, the excuse not to train teachers and those in contact with the young, to raise issues in connection with HIV transmission. It will excise the public and collective voice.

CONCLUSIONS

VCT (writ large) signals a return to a traditional public health approach – where the state/public health takes on a more paternalistic role – and a move away from a modern public health. If people are not coming forward for testing then does the answer lie in provider-initiated testing? Furthermore, many believe that in practice provider-initiated testing will become mandatory testing.

In a traditional public health approach – often marked

by mandatory testing, contact tracing, directly-observed therapy, and occasionally quarantining – people's voices are not heard and their agency is ignored. They are positioned as patients. Will such a move be an effective one in the countries where a modern public health approach appears to be failing? This is the public health dilemma: should there be a return to a traditional public health approach or do we continue working within a modern public health approach?

The imposition of a traditional public health approach is not only likely to fail, but is also likely to feed suspicion and fear. The challenge for a modern public health approach is to address the social, cultural and economic dimensions of health, to address issues of power between and within countries, and to continue to engage with human rights issues.

I would like to conclude with a quote – from a fellow researcher – who works with injecting drug users, Michael Clatts. In 1994 he said the following, but it is perhaps even more apt now:

... that the process has gone terribly awry, that the undaunted search for quick-fix models forces us to crawl into very narrow boxes, that it jeopardizes our ability to see the world as it is, as well as our ability to offer constructive ideas about how to change it. In my experience such models inevitably end up trying to fit the subject to the technology, rather than the other way around.¹³

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HIV testing and human rights

in the era of scaling up access to treatments

BY DAVID BUCHANAN

HIV testing has always been seen as a major tool in the fight against HIV/AIDS. Historically, the visceral reaction to human disease has been to identify the infected – and then DO something about them, something which is usually not a very nice experience for the person tested. The course of HIV disease, however, has taught us that testing for this virus needs to be approached in a way which is sensitive to the lived lives of everyone concerned.

The intimate and stigmatised nature of the vectors of this disease mean that mistreatment of people tested for HIV will only send the disease underground, where it will spread unchecked until, after a decade, it explodes in an epidemic of AIDS. Respect for the rights and autonomy of individuals susceptible to HIV, on the other hand, has been shown to be a driving force for the containment of HIV.¹

It is timely to look at developments in the tension between human rights and the technology of HIV testing and treatment. At the beginning of the 21st century, human rights have, in some quarters, become one great big yawn. Human rights are the sort of thing one gives lip service to, before moving on to discussion of the next free trade agreement.

But we have learned that HIV/AIDS is most effectively combatted in a rights-respecting climate, an environment in which people with or at risk of disease:

- feel comfortable about seeing a health worker and discussing their risk factors and their health
- feel comfortable about getting tested for HIV and other sexually transmissible infections (STIs)
- can learn how to maintain their disease-free status
- can start working on keeping their health despite their HIV or other STI
- can disclose their status without recrimination or discrimination
- can live and work and play without discrimination on the ground of having disease or being at risk for it.

So, for example, it is taken for granted in Australia, but a major contributor to this sort of environment is law. Here we are talking about law which protects the human rights of people with or at risk of disease, laws which are enforceable and which are enforced, laws as basic as compelling health care workers to protect the confidentiality of their clients and patients, laws which say that it is illegal, and you can be punished, for treating a person whom you suspect has HIV worse than someone else in the same situation. These are laws which have historically led to the highest testing rates for at-risk populations anywhere in the world.

Science, of course, is continually developing. In rich countries, we now have highly active anti-retroviral therapy for people with HIV. We also have quicker and, sometimes, more reliable tests than the standard ELISA screening test for HIV. Since 2001, rapid HIV antibody testing has been introduced in North America and in some European countries. Rapid testing has improved to the point where its specificity (the probability that the test will be negative if the specimen is truly negative) is as good as or better than the current HIV point of care tests. On the other hand, at the moment, rapid testing tends to have slightly lower sensitivity to the presence of HIV antibodies. This means there is still a need for confirmatory testing for a positive screening result.

In rich and poor countries alike, there is pressure to make rapid testing more widely available. A big problem with current testing is that results take too long – resulting in patient anxiety and, often, uncollected results. Research has shown that, properly promoted, introduction of rapid testing in HIV/STI clinics results in increased testing rates. The same degree of pre- and post-test counselling is given as is required for ELISA tests.² Properly administered and assuming maintenance of good counselling, rapid testing also has the potential for use in other contexts, such as in preventing perinatal transmission.

What must be firmly resisted, however, is testing in settings not conducive to proper pre- and post-test counselling and settings where counselling is simply not available. Some Americans would like to see testing introduced in gay bars – 'Here's your beer and – oh, by the way, your test result is positive!'

As might be expected, HIV community groups in Australia oppose any dilution of the requirements for informed consent prior to all HIV testing. The need for good post-test counselling remains imperative. It's not just about providing the tools to a newly-diagnosed HIV-positive person for living with their infection. It's about HIV-negative people learning and feeling empowered to maintain that status.

In poorer countries with much, much higher HIV prevalence, however, a far more acute situation prevails.

Anti-retroviral treatments are supposed to be coming on-stream, with the World Health Organization and UNAIDS campaigning for scale-up.³ Other campaigns and mechanisms are being designed, as well, to bring treatments to the countries in the developing world.

It is in that context that there is increasing pressure to identify the infected by testing them. Some 40 million globally are infected with HIV. The scale of the epidemic means there is a treatment and care imperative to save lives. What more precious human right is there than the right to life?

What's more, getting infected people on to treatments can reduce population viral load. Both for epidemiological and for community-psychological reasons, there is an HIV prevention imperative to treat the people with HIV. And how is that going to be done without identifying them by testing?

This has led to further questions being asked:

*In order to identify the millions living with HIV, must the principle of prior informed consent to testing be modified or reduced? Should this epidemic be returned, in the developing world at least, to the more authoritarian strategies familiar to past epidemics? Should every person presenting for healthcare be required to undergo an HIV screening test, perhaps with a right exceptionally to opt out?*⁴

This particular testing paradigm is often described as 'routine testing'. That is, that HIV testing be included as part of the battery of pathology tests which are routinely administered when a person encounters the health care system. In particular, in this way (it is argued) men would be tested, for they are presenting for testing in Africa, Asia and the Caribbean in noticeably fewer numbers than women.

There are many difficult issues around these questions. A feature, however, of the message that pre-conditions for HIV testing need re-thinking is the view that communitarian rather than individual approaches should dominate the response to HIV/AIDS – if only for high prevalence developing countries.

The call for re-thinking the approach of many countries to HIV/AIDS is timely. Whether the human rights-based approach should be jettisoned, however, is questionable. There is no doubt that the approach to HIV/AIDS adopted in many countries has failed. But does this mean that a human rights-based approach has failed?

It is a universal truth that stigma is the greatest obstacle to effective HIV prevention, support and care for HIV-positive people. The model of creating an enabling environment where the social and legal conditions provide incentives for people to know their HIV status has not been shown to fail anywhere. Examples of the association between an enabling environment and containment of the epidemic are abundant. There is no denying the fact that the enabling environment or human rights-based model requires resources, but they are nothing when compared to the loss of economic resources caused by AIDS. Just think of what a different place South Africa would be today if ten years ago it had put the resources it is now

losing to its voracious epidemic of AIDS into HIV prevention and AIDS treatment and care.

Besides, the biggest cost of social campaigns to reduce HIV stigma are cultural and political. Does it have to be the President's son or daughter who dies of AIDS before politicians are prepared to put aside national pride, senses of cultural superiority, fear of sexuality and, let it be said, machismo – and start a conversation with their people about their health?

Before we embrace a communitarian approach to HIV/AIDS which pays less heed to human rights and more regard to identifying and treating the infected, let us ask a few questions.

Who says it is a failure of testing which has led people who need treatments not to be on them? Even in comparatively wealthy countries where treatments are available, most of those who have tested positive cannot afford treatments and that is why they don't get them. In most countries, free programs for providing treatments are small.

Who says that building up a 'bank' of millions of people identified as positive by testing will put pressure on governments to make treatments available, let alone accessible? One would have thought South Africa would be an example of such a country right now, but the stories of its blinkered government are legion. China and India are likewise slumbering giants in relation to HIV/AIDS.

Where are the countries which are failing in their approach to HIV/AIDS which have genuinely worked to address the stigma of this disease, which have genuinely worked to create an environment in which people feel they will be safe going to see, and will get something productive out of a two-way transaction with a clinic doctor?

If men aren't going to clinics in the first place, how is reducing the requirement for informed consent and counselling going to get more of them into clinics? Is it suggested that there should be 'routine testing' in workplaces and schools?

If accessing treatments is the rationale for scaling up testing, will treatment actually be available to those who test positive for HIV, and will it be accessible? In a number of settings, including parts of Africa where treatment is available, it is only where T-cell counts are below 200.

Once it becomes known that going to a doctor or hospital means you will get tested for HIV, will perceptions about testing change? Indeed, will perceptions change about whether you should see a doctor or go to hospital at all? How will reducing voluntariness impact upon client perceptions about, and uptake of, treatment, care and prevention services? After all, don't successful treatment programs require empowerment rather than disempowerment of the individual?

Have those who urge a communitarian approach to HIV testing factored in the inequalities which prevail in the societies for whom these changes are proposed? What is a woman at risk of domestic or community violence to do with her 'routinely' delivered HIV-positive test result

when she goes home? How is 'opting out' of routine testing going to operate in societies where doctors have a caste status vastly higher than they have in Western countries?

Globally there are some 5 million new infections every year. Obviously, getting the infected on to treatments would be a great start. But, in the absence of a real effort to address HIV stigma, how are mass testing and treatment campaigns possibly going to succeed in achieving HIV prevention?

It is known that high-risk behaviour often persists after negative test results – even with informed consent and post-test counselling. How is getting more people into testing, with or without a reduction of their human rights, going to get the vast bulk of the population to modify their risky behaviours?

And if getting more people tested is to be achieved by reducing their voluntariness and autonomy, how will that impact upon transmission prevention where, like treatment uptake and adherence, empowerment of the individual is required?

It is these and many more questions which need to be posed and answered before we embrace technology as the answer to this epidemic. This is particularly in places where efforts to implement a human rights-based approach have not seriously been attempted and where an adequate and integrated health care infrastructure has not been established.

Technology has its place. Research being done into provision of anti-retroviral treatments in resource-poor settings has demonstrated clearly that sustainable treatment programs can be designed and put in place in developing countries.⁵ There is no reason why they can't be integrated with sustainable HIV prevention and other health care programs.

At the same time, however, experience in both developed and developing countries shows that engaging communities – especially people with HIV and those most vulnerable – is central to scaling up HIV testing, counselling and treatment, and particularly to prevention.

At the end of the day, unless the individual intuits that there is something in it for them, and for their community, a technology-based response to HIV/AIDS will not succeed. A human rights-based approach is not just morally superior: It is more likely to work.

To that end, instead of just more testing, the imperative today is for a rejuvenated effort to get policy makers:

- to give HIV/AIDS the priority it needs,
- to put in place the infrastructure needed to deal with HIV/AIDS, and
- to bite the bullet and create the kind of caring environment in which people have a reason to learn their health status and to take steps to protect themselves, their loved ones and their communities.

In other words, the response to the burgeoning global toll of HIV infection should be for policy makers to see a human rights-based approach as integral to public health, rather than in opposition to it.

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Ethical issues in trials of HIV prevention

BY JOHN KALDOR AND IONA MILLWOOD

In many ways there could be no more paradigmatic a model of the course of human illness than HIV/AIDS. People start off 'healthy' (whatever that means), or 'disease free' to use medical terminology, which usually means that a person hasn't got the disease that is of particular interest. Then, if exposed to 'the virus', they become infected, and from then on, there is a simple and brutal progression that was well understood within several years of the first appearance of the epidemic; viral infection is not eliminated, and a probability distribution is set in place that, without treatment, will lead an infected person down the track of disease progression and death in an average time of about ten years.¹

This apparent continuum conceals a stark divide that is at the heart of a number of important debates that have emerged about our global responses to HIV/AIDS. Put quite simply, it would appear that people have choice, or agency in whether they move from 'healthy' to 'HIV positive', but once they are in the box labelled HIV positive, biology takes over; and only treatment can interfere with the inexorable march of immune destruction.

Some people might argue that in countries or populations with high transmission rates, there is really no such divide. Despite the notional ability of people to choose to avoid infection, the social and cultural matrix in which they live can apply just as much determinism in the direction of acquiring infection as the virus can do to their immune system once they become infected. In populations such as women attending antenatal services in KwaZulu Natal, sex workers in Tamil Nadu, and injecting drug users in several regions in Russia, with up to half the people infected², it is hard to argue against this analysis.

This influences the two sides of the debate among people who are developing and conducting HIV prevention studies that attempt to test some kind of biological intervention, such as a vaccine. On the one hand, some see prevention studies as really no different from treatment studies. We need to identify an appropriate group of people designated to be 'at risk' of getting HIV or progressing from HIV to more advanced disease, make sure that each individual understands and consents to the trial with all its potential risks and benefits, and then randomly assign them into two groups for comparison. The key is about individual informed consent, and the role of social and community factors is very much in the background.

On the other hand is the perspective that prevention trials have implications and impacts that go far beyond the individual, and therefore require the involvement of a much broader engagement in the consent process. If we accept this position, we are immediately led to the consideration of a whole new range of strategies and structures for deciding whether, and how, a prevention study is to proceed.³

One of the biggest concerns in prevention studies is the possibility that the agent under investigation might lead people to change their behaviour, thus increasing the likelihood of becoming infected with HIV. This issue is sometimes claimed to be a contradiction between the obligation of investigators to provide the best standard of prevention to study participants and the need for infections to occur during a study for a result to be obtained. In fact, it should by now be clearly understood that all participants in prevention studies should be offered access to the best available means of prevention, which generally means information, counselling, condoms and clean injecting equipment; although there might still be debate about how much counselling and what kind.⁴

The limited amount of information that has accumulated from trials of vaccines and vaginal microbicides has so far not indicated that there was any overall increase in risk behaviour amongst trial participants.⁵ In fact, the answer to this question will not, and cannot, emerge clearly from randomised trials. Once people start to use a prevention agent with full knowledge of its prevention benefits, the situation may be entirely different, and unlike the issues of biological efficacy and toxicity, the extent of any change in risk exposure following the use of a prevention agent may vary considerably across populations.

A second issue is the very meaning of informed consent. Since the Helsinki Declaration and its successors, the principle of informed consent has underpinned all forms of human health research, and on the surface it would seem to be an unambiguous and non-negotiable entity.⁶ The problem with this model is its assumptions of equality in communication, and equality in power, between the researcher and the researched.

It is not only in developing countries that it is reasonable to ask whether a person who has been asked to provide informed consent really has been informed and really has consented; the same question may equally arise in highly resourced countries. Literacy and education levels clearly must be taken into account in providing a person with information about a study, but these can tend to be over-rated as barriers to informed consent.

Careful development of study materials and processes should produce a communication strategy that will let people know what a trial is about.⁷ Ultimately, it is the much harder-to-define cultural and social standing of a person that is likely to determine whether or not that person is able to make a true choice, and a choice that is truly informed, about study participation.

A closely related issue is the role of a person's community in providing consent. At a formal level, the institutional ethics committee provides a community level judgment on the validity of a proposed study, but there may be many community voices that are not heard on the ethics committee. Furthermore, no study design will ever meet universal acceptance in every aspect of its conduct, particularly in an area as controversial as HIV prevention. So, as the plans for a study unfold, the researchers have to weave a careful path between consulting authorities, communities and individuals as they develop the consent process.⁸

A further ethical issue that has dogged prevention studies in limited-resource settings is the extent to which HIV care and treatment should be offered to people who are detected as having HIV infection in the course of the trial.⁹ It is important to make a distinction here between those detected as HIV-positive at enrolment and those who become infected in the course of the trial.

In high-prevalence settings, there may be many people in the first category and far fewer in the second.

It seems clear that the trial has an obligation to provide voluntary counselling and testing to the highest standards, consistent with international best practice, but has no obligation for HIV care and treatment to those already positive and not eligible for the trial. Indeed, if prevention study sites were to be perceived as playing this role, they would immediately become magnets for people who knew or suspected that they had HIV infection and wanted to ensure treatment access. While researchers can serve as effective advocates for expanding treatment access in resource-limited settings, they cannot widely offer it through the very finite resources that are available for a study.

For people who are HIV-negative at screening and who consent to participate, the situation is very different, as they establish a long-term relationship with the investigators that carries with it the obligation to undertake medical care for conditions that arise in the course of the study, including treatment for HIV infection, in a manner that is consistent with national guidelines.¹⁰ Although the funding arrangements for some prevention studies may still exclude such care and treatment, the investigators in a number of developing countries are finding ways to ensure referral to qualified medical services.¹¹ The rapid scale-up of access to antiretroviral therapy has greatly facilitated the identification of such services in many developing countries.¹²

The issue of longer-term care and treatment for study participants, beyond the period of a trial, is a more difficult one in developing countries, where mechanisms for health insurance or other forms of universal health coverage are largely absent.¹³ Whether the study involves looking

at infant vaccines or malaria drugs, there is currently no obvious means for participants to obtain health care, or indeed seek legal redress, for any trial-related illness or injury that may come to light after the trial has closed.¹⁴ Establishment of compensation funds, purchase of insurance policies, or long-term funding of local clinics are three alternatives that have been proposed but not yet adequately debated and certainly not resolved.¹⁵ It is really not good enough for trial sponsors in developing countries to expect participants to absolve them of all responsibility for trial-related harm, through the simple step of signing informed consent.

The distinction between prevention and treatment research may be starting to blur again. The latest generation of vaccines under investigation, disappointing as their early results have been, do not aim to actually prevent infection, but rather to assist the immune system in controlling the virus¹⁶; more like a treatment. Conversely, the drugs that have proved to be so miraculous in treating people with HIV infection are now being considered for use as prevention agents¹⁷, whether by reducing virus level in people with infection, hence making them less infectious, or by interrupting the chain of cellular events in people who are exposed to the virus, so that it does not become established.

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Power, prejudice and prevention: can research advance social justice?

BY BRIDGET HAIRE

HIV is both a preventable and a treatable disease. The current tools that we have for both treatment and prevention are imperfect, but the most confronting injustice is the lack of access to these tools in the developing world where most HIV infections take place.

HIV is as interesting in the abstract as it is appalling in human terms because its epidemiology maps relations between people and articulates the system of power relations in which we live. There was a prevention slogan about five or six years ago: 'HIV doesn't discriminate. Do you?' It was part of a program aimed at reducing the stigma that attaches to living with HIV, and marked a shift in the prevention discourse from a focus on 'risk groups' that marked members of those groups in a negative way, towards the identification of risk practices. This shift was symbolic and important and it represents a careful reframing of the truth – but, while it is true, the paradox is that it is also untrue: HIV does appear to discriminate. It disproportionately affects the poor; the marginalised, the dispossessed and women, as was highlighted on World AIDS Day 2004.

Here I want to address issues involving women and biomedical research, particularly HIV prevention research. I want to suggest an agenda for research which many would argue is far beyond its scope. My contention is that research is not value-neutral and that it affects the communities in which it is practised. Therefore, there is an opportunity – and I would argue an obligation – for researchers to consider their work as a social intervention that has potential for advancing or impeding social justice.

It is not my intention to throw stones at researchers. Amazing things have been achieved by medical research in this field. Certainly, we don't have a vaccine or a cure, but we do have effective treatment. In 1996 it was established that combination antiretroviral therapy could suppress viral replication to allow immune recovery, leading to Lazarus-like transformations in people with HIV.

Article 25 of the Universal Declaration of Human Rights states that everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including medical care. In 1996, however, it seemed that in practice the exercise of this 'right' would be determined by the accident of birth and/residency. Years later, an estimated three million people per year are dying of what is a treatable illness, but there has been progress.

At the International AIDS Conference in Vancouver in 1996, presentations lurched between the gripping story of triumph in the clinical science stream and plaintive cries

from those who understood that these life-saving treatments would not be available to themselves or their loved ones. Four years later, at the International AIDS Conference in Durban, the calls for treatment access held centre stage, while HIV science took a backseat. Economics was the science under scrutiny – specifically the claim that antiretrovirals were prohibitively expensive.

Three years later, the World Health Organization, which had previously backed drug-company controlled discount schemes, launched its ambitious '3 x 5' program'. While it is clear that this goal will not be achieved, at least it is a recognition that the right to treatment takes some kind of precedence over the protection of patents and profits. There are many implementation issues with this program, but I think it is necessary to see the enormous leap in thinking it encapsulates – that the right to treatment is not just abstract, but a real goal.

Research has an important role to play in this brave new world where equitable treatment access – again, for a limited few – is on the horizon, if not on the table. Researchers in Australia have been at the forefront of this, designing programs that test ways of making treatment more affordable, by looking at ways of reducing the real cost of treatment – laboratory infrastructure and labour-intensive procedures – rather than artificially-inflated drug costs. This is the kind of research that has human values at its core.

But leaving aside therapeutic HIV research, the inclusion of women in research into prevention technologies has been a vexed issue.

UNAIDS tells us that women account for about half of the world's population of people with HIV, but young women and girls are 2.5 times more likely to become infected than male counterparts. Does that mean that the face of HIV is increasingly female?

Article 12 of the International Covenant of Economic, Cultural and Social Rights says, 'The realisation of women's right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.'

The comments on the Convention on the Elimination of All Forms of Discrimination Against Women goes further, specifically discussing HIV/AIDS:

Adolescent girls and women in many countries lack adequate access to information and services necessary to ensure sexual health. As a consequence of unequal power relations based on gender, women and adolescent girls are often unable to refuse sex or insist on safe and responsible sex practices.²

These comments underscore the fact that while HIV infections in women do not outnumber those in men – and quite the opposite – that women are nevertheless more vulnerable to HIV on two counts. Firstly, the systematic oppression of and discrimination against women means women have less control over their own sexuality and thus exposure to HIV. Secondly, vaginas are biologically more vulnerable than penises; the anus is the equal opportunity orifice for both men and women.

But at the same time that the intertwining of human rights and health is being acknowledged, there is a disturbing trend in various national HIV policies toward greater authoritarian interventions. Singapore has considered compulsory testing for HIV in pregnancy. The implementation of 100% condom programs in Thailand and Cambodia sounds like a good idea at an intuitive level. However, these are not health promotion programs aimed equally at workers and clients, but punitive programs that give police greater control over sex work with the loss of personal dignity, forced sexual health checks and manifold opportunities for corruption. 100% condom use in brothels is a great idea, but not at this cost. Increasing condom use in brothels should be a way of empowering workers and improving sexual health in a consensual way, one that recognises that sex worker too have the right to the inherent dignity of the human person.

MOTHERHOOD

HIV has been an extraordinary catalyst for testing drugs in pregnancy. However, a great deal of the focus has been on preventing transmission to the infant rather than treating the woman for her own sake – although this emphasis too has changed and is changing more. Programs for preventing mother-to-child transmission have been blighted by allegations of being unethical.

Despite the landmark ACTG 076³ finding that mother-infant transmission could be reduced from 24% to 8%, other mother-to-child transmission studies were conducted in developing countries using other, cheaper regimens against placebo, rather than the new best-practice standard set by ACTG 076. The justification was that the 076 treatment regimen was unobtainable for the developing world. Part of the justification was that women present later for antenatal care in the developing world so the earliest dose in the 076 regimen simply wouldn't work. But the major factor was the cost of drugs. The intention, I think, of the researchers was a noble one – to find a proven, affordable intervention. However, the assumption that the expense of the drugs was immutable was faulty; drug pricing can change when demands are high enough.

In the developed world, prevention of transmission from mother to baby has become more sophisticated and more successful, with combination therapy now standard and rates of transmission less than two percent. In the developing world, the utility of some cheaper regimens has been established, but one of the popular cheap interventions involves nevirapine (Viramune) monotherapy. Using nevirapine in this manner has been shown to cause clinically significant resistance in the mother, and cross-resistance across the class of non-nucleoside reverse transcriptase inhibitors, significantly limiting treatment options.

Mother-to-child prevention works best when the infant is given a prophylactic dose of an antiretroviral in addition to the drugs that lower the mother's viral load. This essentially provides a 'proof of concept' that pre-exposure prophylaxis may work to prevent HIV transmission in other contexts. Along with microbicides and vaccines, pre-exposure prophylaxis is one of the new prevention technologies now being tested.

Proving the efficacy of vaccines, microbicides and pre-exposure prophylaxis involves selecting a trial population where incidence of HIV is high enough to ensure that even if participants on the trial modify their behaviour to some extent, that exposure and subsequent infections will occur. Such populations are nearly always to be found in the developing world in countries with generalised HIV epidemics, though some high-risk populations from developed countries with concentrated epidemics (such as gay men) may form part of the cohort.

Trial participants are then randomly assigned to receive that active agent or a placebo at a ratio of 1:1, but all who enter the trial are provided with condoms and counselling about safe sex practices – 'best-practice' prevention. The provision of clean injecting equipment should also be part of this package, but due to murderous political obstinacy, this has not been the case in vaccine trials to date.

There is now a growing consensus that people in prevention trials who seroconvert should be guaranteed access to combination antiretroviral therapy. The advent of the '3 x 5' program, together with other treatment access initiatives, means that this is now more feasible, with the infrastructure for the trials complementing infrastructure needed to provide treatment.

In a presentation at the Seventh World Congress in Bioethics⁴, bioethicist Ruth Macklin, who has been providing guidelines on priority setting for the rolling out of '3 x 5', included participants in prevention research as one of the priority groups.

PREVENTION FOR WOMEN

Women have much to gain from biomedical HIV prevention technology, not because current behavioural prevention doesn't work, but because women do not control the use of it and because factors such as violence against women, rape in marriage, the view of marriage as an agreement to provide sex for husbands upon demand, the economic necessity of sex work and the fetishisation of virgins (or young girls of 'virginal' aspect) substantially increase vulnerability.

While men generally have some control over their risk behaviour, in many contexts women do not. Male behaviour – and women who collude with the oppression of other women – needs to change, but this is simply not going to happen in the immediate future. Therefore technologies that can be used at a woman's discretion, and which are not detectable by male partners, are desperately needed.

Historically, women have been greatly under-represented in biomedical research. Aspects of this are changing, but women 'of child-bearing potential' are routinely asked to use contraception and subjected to multiple pregnancy tests throughout trials. The VaxGen efficacy trials of the failed HIV vaccine enrolled only a minority of women, and contraception was a requirement.

In order to develop prevention technologies that are safe, effective and acceptable to women, they need to be involved in every stage of development. More than lip-service needs to be given to prioritising women's inclusion in research. Finding ways to accommodate women's needs, such as childcare and support for other caring responsibilities, needs to become part and parcel of good research practice.

In addition, the safety of prevention technologies needs to be established in pregnant women, breastfeeding women and adolescent women. While the prevention of possible birth defects is important, the pendulum has swung too far the other way, creating an unfair barrier to participation. Although there are sound reasons for preventing participation of pregnant or lactating women and adolescents in the early phases of product development, it would be both tragic and absurd to establish that a technology works without knowing whether it is appropriate for women at risk of HIV through all predictable life-stages. The women who would suffer most from lack of knowledge about effects in pregnancy would be those who are most vulnerable, repeating the vicious cycle.

A possible program is outlined below.

Pre-clinical:

Teratogenic potential evaluated in animals

Phase I:

Include equal numbers of women and men, or a majority of women. No pregnant women. Female-specific adverse events require careful study.

Phase II:

Pregnant women excluded, but women planning pregnancy within trial follow-up period included. Should pregnancy occur, a special monitoring protocol would be followed.

Phase III:

Pregnant women included provided that:

- participants have been fully informed about potential risks;

- a special pregnancy monitoring protocol is in place;
- an information-share agreement can be made with trial doctors and the woman's treating obstetrician.

Phase IV: Post-marketing

Formal post-marketing studies should be a precondition of licensure for HIV prevention technologies, with particular emphasis on gathering data on use in pregnancy/lactation.

The nucleotide analogue tenofovir (Viread), which is being evaluated as pre-exposure prophylaxis, has a generally good safety profile. However, it has a shaky safety profile regarding its appropriateness in pregnancy in otherwise healthy HIV-negative women. (If being used by populations to prevent HIV, then its use in early pregnancy in HIV-negative women would logically occur.) Tenofovir is associated with decreased foetal growth and reduction in foetal bone porosity in monkey studies, and bone demineralisation with chronic use, particularly in children. But there has been deafening silence on this aspect of the drug in discussions of the pros and cons of pre-exposure prophylaxis. This suggests that it may not be the HIV prevention equivalent of the contraceptive pill, and that other second-generation agents will be needed.

HIV prevention research has great potential for bringing new resources into areas where HIV is endemic, improving medical care and facilitating access to HIV treatment. A narrow focus on testing products without careful regard for the needs of the populations upon whom they are tested, however, would constitute exploitation.

In the meantime, we have to apply pressure to get the interventions that are known to work to be deemed acceptable by governments and policy-makers. If nations are truly committed to stemming the epidemic, how can prohibition against needle programs be justified? With an epidemic fuelled by injecting drug use in many parts of Asia, when is this proven intervention going to become policy? Will it ever?

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Re-thinking human rights and the HIV epidemic:

a reflection on power and goodness

BY ELIZABETH REID

The dominant discourse on HIV and human rights has been drawn from a legal paradigm for which international human rights law has provided the theoretical and legal framework. As a result, attention has been focused on the ways in which human rights law has been violated.

Extensive descriptions of HIV-related human rights violations in different cultural, economic and political contexts have been documented. These inventories are then used to confront and shame the perpetrators, a classical legal practice and the dominant practice of human rights activism.

The legalistic conceptualisation of human rights has been successful in that it has led to changes in policies and behaviours. Mark Heywood¹ argues that in many countries there is now legislation and policy protecting the human rights of people infected/affected by HIV. Human rights arguments have had an impact on global thinking, the conduct of pharmaceutical companies and, in some cases, the practices of governments. However, he argues, the degree to which these protections benefit people is patchy and they have had little tangible impact on the lives of poor women and children.

One consequence of the legalistic approach to human rights has been that little or no work has been done to document the ways in which HIV-related human rights have been upheld. Yet early in the epidemic, at the first Conference on Health and Human Rights at Harvard University, those present were challenged by the Professor of Public Health of Zagreb University to develop an activism of praise. He pointed out that, where, as in his country, human rights violations were widespread, a practice of praising those who honour and respect human rights might be developed. This, he argued, would reinforce such behaviour and provide guiding narratives, accounts of respect and support across difference, of defiant bravery, of quiet resistance.

A practice of praising builds on the goodness in people. It gives hope to those who might want to live according to particular sets of values. It gives an account of the exercise of responsibility and creates the possibility of collective integrity. Because of this, it could be influential in bringing about the benefits and social changes lamented by Mark Heywood. A practice of praising would also bring a particular moral dimension to the legal paradigm and its confrontational forms of advocacy and activism.

A further consequence of the practices of the violations approach is that less attention is paid to developing an understanding of the social and economic conditions which create the violations. Paul Farmer writes:

*'The struggle to develop a human rights paradigm is one thing; a searching analysis of the mechanisms and conditions that generate these violations is quite another. Without understanding power and connections, how do we understand why rights are abused?'*²

Farmer argues that violations of human rights are symptoms of deeper pathologies of power 'linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm'.³

The pathologies of power that determine who, amongst those infected or affected by HIV, will suffer from violations of their rights have not formed a part of the human rights discourse on HIV⁴, nor are they often addressed in HIV programming. The social conditions in which they are expressed are usually considered to be slow and difficult to change, too slow for the HIV epidemic.

Consider the pathologies of power which shape women's lives within the epidemic in terms of protection, care and support. Violence to women, child brides, rape, inadequate reproductive services, misogyny, the abduction of women, the lack of valuing of women, and more, practices such as these spread the epidemic. The same pathologies result in women having limited access to care and treatment, particularly to antiretroviral therapies, causing untold trauma to them and to their children. The language of human rights is a challenge to these pathologies of power; but they are normally regarded as deeply socially embedded and difficult to address. What is needed for a human rights-based approach to the HIV epidemic are timely changes in the social conditions which determine human rights abuses.

An approach to HIV-related social change which draws on the work of Paulo Freire has recently entered the HIV literature. Stephen Lewis has singled it out as 'the stunning

revelation of community conversations'.⁵ In a visit to rural Ethiopia mid-2004, Lewis sat with two communities, listening to them converse about the social conditions which were spreading the epidemic. One conversation involved 200 villagers who had been meeting once a fortnight for a couple of months; the other involved 15 or 20 people, with dozens of onlookers, who had been conversing for more than a year. Both communities were in a predominantly Islamic region.

The community conversation approach draws on traditions of talking things through and collectively deciding how to handle them. Community conversations are structured approaches to helping communities become aware of the ways in which their social norms, values and practices spread the epidemic in their midst, marginalise and humiliate those affected, and lessen the community's capacity to survive the epidemic. The methodologies used create a consciousness of these factors and then assist the communities in deciding how to respond.

The subject matters that Lewis heard publicly discussed in these community conversations 'without so much as a touch of embarrassment or shyness' included female genital mutilation, sexual violence, bride sharing, child abduction, early marriages, condoms, living with HIV and women's rights.

The results were astonishing. In one community, where female genital mutilation had been universally practised, it was down to 10 to 15 per cent within a year as a result of the conversations. An Islamic leader and 130 other men decided to be tested for HIV in order to set an example for others. Young girls talked openly about their rights as women and strategies they had adopted to protect themselves from HIV infection. Lewis commented:

*It was all quite extraordinary. We talk forever about countries where the level of awareness of HIV is very high but behaviour change is negligible. These community conversations have resulted in huge behaviour change. I have always believed that it would take generations even to show a willingness to address gender equality. Here it seems to have happened virtually overnight!*⁶

What makes these community conversations so effective in addressing the pathologies of power? The answer lies in the creation of a structured environment in which communities are able to reflect upon norms and practices, inclusive spaces in which all their members – irrespective of gender, age, class, status, ethnicity, etc. – are able to voice their concerns and opinions, and in which together, as a group, they seek to find ways to protect themselves from the epidemic.

These conversations harness the power for good in a community and build on human potential and human virtues. They acknowledge human frailty without seeking it out to shame or confront. They enable practices of collective integrity and responsibility to arise.

They are, in the words of Michael Ignatieff, a practice of human rights as aspirational. They assume that people aspire to a world in which all human beings are respected, where their persons should be inviolable, and where they have enforceable rights by the very fact of being human

beings.⁷ These aspirations are made more possible through the sanctuary of these conversations, a sanctuary in which it is the pathologies of power which are confronted and changed.

The pathologies of power that determine who, amongst those infected or affected by HIV, will suffer from violations of their rights include a multitude of other offences against human dignity: deprivation, neglect, indifference, racism, unemployment, sexism, ill-health, under-education, violence and abuse. Can these be addressed and changed through methodologies of community conscientisation and empowerment?

Many of these offences are not amenable to community-based problem-solving approaches. Their roots lie beyond communities as well as within them. Within communities the roots are found in systems of social relations; within societies, structural violence is embedded in the institutions of the society and economy. In what ways can these pathologies be understood and addressed?

We have been reminded recently that, as long ago as 1969, Johan Galtung wrote of the condition of structural violence in which people are denied decent and dignified lives because their basic physical and mental capacities are constrained by hunger, poverty, inequality and exclusion.⁸ Structural violence is violence carried out systematically by those belonging to a certain social order. In these situations, praise or blame cannot be attached to individual actions alone.

Violence of this type is built into the structure and functions of a society. Hence, it manifests itself differently in each society, for it depends on each country's historical, political and cultural circumstances. Structural violence leads to acute violence. Genocide might be its manifestation in Rwanda in 1994, or it might be the violence, aggression and corruption in Papua New Guinea in recent years.

In PNG, there is a rapidly expanding and generalised HIV epidemic; there is a breakdown in law and order; there is the constant threat of violence; increasing numbers of politicians and senior bureaucrats are being named as corrupt. To outside eyes, these are often seen as local tragedies locally derived.

The concept of structural violence traces how inequity is structured and legitimised over time. It renders visible the structural power relations which have contributed to how the present has come to be and who within the present benefit or are debased. It enables the questions to be posed: who are the untimely dead? In PNG, these include the women dead in childbirth, the women raped and discarded, the murdered, those dead of treatable diseases and conditions, the burnt, and, increasingly, the dead of HIV. These are the victims of structural as well as local violence, those whose human rights have been violated in multiple ways.

A 'searching analysis of the mechanisms and conditions that generate these violations' raises the question of how we understand this world of violence and degradation. Too often it is 'seen' and understood through the creation of 'the Other'. From the description of what is, an elision is made to They: 'They are a violent people'; 'They have

little or no respect for human life'; 'They are rascals and rapists'; and so on. The state of their world becomes what is seen and ascribed causally to them. This way of understanding their world justifies the neglect of their human rights.

The concept of structural violence provides us with a way of understanding such violence and lawlessness which refuses the elision from description to the predication of these qualities to people. Rather; anger; despair; frustration, cynicism, normlessness, confrontation are seen as manifestations of structural violence, as outcomes of deprivation, not states of being.

The validity of such an analysis is borne out by a recent study of crime in NSW. A report prepared by the NSW Bureau of Crime Statistics and Research showed that falling crime rates in NSW (12 out of 16 major categories in the last two years) can be linked to higher wages among young men and a drop in long-term unemployment. The Director of the Bureau argued: 'Low wages and long-term unemployment are significant contributors to crime. When they improve crime tends to fall'.⁹

Historical and political conditions in PNG have created the systems and institutions which create deprivation and dysfunctionality. The social outcomes include a paucity of social mechanisms for dealing with conflict, concepts of women as disposable property, and pervasive and chronic unemployment, especially among young men. These deprivations contribute to the violence, aggression and corruption which fuel the HIV epidemic.

Pathologies of power result from and cause structural violence. Structural violations in a society create the conditions under which the epidemic expands and which skew or prevent access to care and treatment. A HIV-related human rights discourse in this analysis would encompass social and economic rights such as the right to gainful employment, the right to adequate wages/incomes, to education, to health and more. People have a right not to be systemically and chronically deprived of their capacity to lead decent and dignified lives.

Such an HIV related human rights discourse could also encompass a practice of praising which would lead to an understanding of people's resistance to being overwhelmed by structural and local violations in their society. Such an understanding resists an analysis in terms of human faults and failings and is open to a belief in human goodness.

A discourse on HIV and human rights which builds human goodness and integrity could lead to effective approaches to addressing the HIV epidemic. It would allow us to aspire to a world where human rights are respected and to an activism of praising, emulating and supporting.

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HIV and human rights: through an East African prism

BY MICHAEL BURKE

I recall the story of the Maasai man who attended the clinic. He sought out the antibiotic tetracycline. He referred to it as 'rangi mbili' (Swahili for 'two colours'). Tetracycline comes in a white and green capsule. He explained it must be a more powerful medicine than others, as a medicine of two colours is obviously more powerful than a medicine of only one.

I also recall the story of the hippopotamus that recently visited an east African capital city. Hippos lived nearly two hundred kilometers away. But one evening, very unexpectedly, a hippopotamus was seen strolling near the city's main roundabout. The media followed this story for several days. There was much conjecture about the real significance of the visit. The teller of the tale, a professor of obstetrics, shared that he felt the beast must be travelling an imprinted, almost forgotten, ancestral migratory pathway. The reincarnationalists interpreted that the hippo's location next to mosques and churches demonstrated an interest in higher matters and indicated much promise for a next reincarnation. One religious group took solace that the hippo sought shelter in their carpark. However, the majority view recognised that a hippopotamus is well known as a magical creature of significant healing powers, and of course the hospital was nearby. Obviously the hippo was travelling to the hospital on a quest.

HIV is situated in the social and sexual lives of people. These lives are embedded within cultural and gender narratives. These narratives are often remote from the world of institutionalised health care, scientific research and international legal documents. Human rights have emerged as a key discourse which is used to frame, monitor, and evaluate various strategies and initiatives.

This is a discourse of the developed world that is now a globalised discourse, presented as hegemonic in international forums. The discourse of human rights is well placed to facilitate an international dialogue between partners that can embrace its history and significance. Many development issues have been and can be facilitated within a human rights framework. A human rights approach is predicated on an established and influential legal system based on enlightenment principles. While a human rights approach may, or may not, resonate in the capital cities of developing countries it will struggle to do so in the narratives of rural villages or in many smaller urban communities.

Foucault¹ talks of how a discourse, such as human rights, is an embodiment of years, if not generations, of iterative dialogue. A term such as human rights exists as a signifier

of a dialogue that stretches richly through time and space. Berry² provides useful constructs to address the issues of similarity and differences between settings. 'Etic' constructs are present in identical or almost identical form in many settings, and 'emic' constructs are found in a single setting only. Within the domain of international communication, three kinds of equivalence may or may not be present³: semantic equivalence across languages⁴, conceptual equivalence across cultures⁵, and normative equivalence across societies⁶.

There may well be a way to gain a semantic equivalence for 'human rights' in various languages, e.g. 'haki za binadamu' (Swahili). However, conceptual equivalence, where concepts are equally meaningful to people in different cultures, is often lacking. For example, an east African villager's identity is conceived as more communal than individualistic. Individual rights are a relatively new concept.

Human rights approaches work well in settings where there is a norm of valuing multiply-located points of view. In patriarchal communities, where deviation from a norm makes an individual vulnerable to community exclusion, normative equivalence is lacking. Much of Tanzanian society values acquiescence over assertiveness. A human rights approach is more consonant with settings where assertiveness is valued over acquiescence. Human rights resonate well with notions of self-efficacy and less well with notions of fatalism. Fatalism, rather than self-efficacy, is more the historical norm in east Africa.

Human rights, if viewed through an epidemiological prism, are associated with efficacy and probably effectiveness, but seem to score less well on the measure of empathy. I use empathy in the sense of conceptual and normative equivalence. Human rights as a signification has limited conceptual or normative equivalence between a community represented in an international forum and an equally important community represented in a local village meeting.

Recent events where older women in western Tanzania have been stigmatised and discriminated against as witches highlight the dissimilarities rather than the many similarities

that exist within our globalised world. In Tanzania, a country of nearly forty million in east Africa, the discourse of human rights has iterated for a relatively short period of time. Human rights have an internal hierarchical network of subcomponents. In Tanzania, the right to elect has been established over the past decade. The right to be elected is still seeking its confirmation. Issues of rights to education and health care are only commencing their discourses. Gender and human rights continue to be contested. Some components of a recognised human rights discourse have been adopted, but many other elements are only commencing their campaign for acceptance. Others have yet to even make an initial appearance on stage.

This is not to discredit an approach based on human rights, but merely to place human rights within its context and recognise its constraints. A possible way forward is to regard our approaches as taking place within three interlinked levels: international, national and community.

The UNAIDS 'three ones' approach to HIV/AIDS – based on the promotion of one national policy, one national strategy, and one national monitoring and evaluation system – is well-complemented by a human rights approach. However, implementation and needed social change takes place at a more grass roots level. Hence to complement the national level approaches, a similar set of entities is needed at community level.

Experience within an east African context hints at possible components of this community approach. Comparison and contrast within the trajectory of responses in the three east African nations of Kenya, Uganda and Tanzania yield tentative lessons. All three countries have generalised epidemics.

Tanzania is the largest, the poorest, and the most peaceful. It is the least economically developed. Civil society has been weak and there is sometimes suspicion between government and non-government agencies. Recently there have been steps to improve in these areas. The arrival of antiretroviral medicines (ARVs) offers hope to many. So far, 3000 have access, but this contrasts with the target of 300,000 by the end of 2005. The arrival of ARVs will hopefully facilitate dialogues that give agency to communities and not lead to disempowerment.

Uganda is a recognised trend-setter. Post-civil war, government sought to collaborate with civil society. Mr Museveni, the president, travelled around the country and talked about AIDS. He challenged people and they listened. Champions emerged. Civil society grew very fast. This was encouraged. A deep and dense dialogue developed. Prevalence fell from 26 to 6 per cent – although this is still too high. All of this occurred before ARVs, and before human rights approaches were placed centre stage.

Kenya has a significant epidemic, but has not yet fully engaged with HIV issues.

The 'three ones' at national level are needed. A human rights framework is valuable. What are needed are parallel entities at community level. These could include coalitions, conversations and courage. Conversations are needed

so silence is overcome, and fear addressed within community. People need to regain confidence in their capacity to be agents.

A human rights approach that facilitates networking, empowers the voices of civil society, and ensures them a secure place within national dialogue is helpful. Community dialogue needs to be grounded within the discourses and narratives of community life – social, traditional, gendered, political and religious. It may well be too long a path to position human rights as the primary narrative. There is no magic bullet. Strengthening of community action can be enhanced by a human rights approach. However, solutions cannot be imported; they need to be grounded within local stories and practices.

While a human rights approach is assumed to be the best way forward, there are several concerns that will need to be addressed as our understanding matures. Many questions arise. These include the following: Do programs that verticalise and privilege HIV programs fully acknowledge that those equally unwell from other diseases are not similarly privileged? Can a human rights approach restrict itself to addressing the narrow issue of access to preventative and curative strategies while not acknowledging contributory factors of restrictive trade and knowledge access?

While the human rights approach is currently hegemonic, it will continue to hold this position only if it is able to assert its efficacy, effectiveness and empathy into the future. I personally feel a multi-level context-responsive strategy will in the long term better serve at community level.

While a human rights approach currently offers a great amount, it must continue to iterate with its context.

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