Righting Stigma:
Exploring a rights-based approach to addressing stigma

Frans Viljoen (editor)

AIDS and Human Rights Research Unit, University of Pretoria, 2005
The financial assistance of the Norwegian Centre for Human Rights is gratefully acknowledged.
RIGHTING STIGMA:
Exploring a rights-based approach
to addressing stigma

Frans Viljoen (editor)

UNIVERSITY OF PRETORIA

AIDS and Human Rights Research Unit, University of Pretoria
2005
CONTENTS

6  List of abbreviations and acronyms

7  Introduction
   Frans Viljoen, AIDS and Human Rights Research Unit, University of Pretoria

12 Chapter 1:
   “If you (be)come HIV positive, you will lose your human rights.” 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
   Farhana Zuberi, Consultant, Centre for the Study of AIDS, University of Pretoria

50 Chapter 2:
   Beyond “bitches and prostitutes”: Folding the materiality of gender and sexuality into rights-based HIV/AIDS interventions
   Amanda Alexander and Mandisa Mbali, Centre for Civil Society, School of Development Studies, University of KwaZulu-Natal

64 Chapter 3:
   Disclosing in an age of AIDS: Confidentiality and community in conflict?
   Frans Viljoen, AIDS and Human Rights Research Unit, Faculty of Law, University of Pretoria

94 Chapter 4:
   HIV testing and voluntary counselling in the context of stigma
   Ncumisa Nongogo, Lawyer and training coordinator, AIDS Legal Network

116 Chapter 5:
   “Hey Miss AIDS, when are you going to receive your social grant?”: The right to have access to social assistance: HIV/AIDS and disability grants
   Farhana Zuberi, Consultant, Centre for the Study of AIDS, University of Pretoria

132 Chapter 6:
   Promoting the right to health care services for people living with HIV/AIDS in rural and peri-urban communities
   Jennifer Joni, Private consultant on HIV/AIDS

150 Bibliography
# List of Abbreviations and Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACHPR</td>
<td>African Charter on Human and Peoples’ Rights</td>
</tr>
<tr>
<td>AIDS</td>
<td>acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ALP</td>
<td>AIDS Law Project</td>
</tr>
<tr>
<td>ART</td>
<td>antiretroviral treatment</td>
</tr>
<tr>
<td>ARV</td>
<td>antiretroviral therapy</td>
</tr>
<tr>
<td>BALR</td>
<td>Butterworths Arbitration Awards</td>
</tr>
<tr>
<td>BIG</td>
<td>basic income grant</td>
</tr>
<tr>
<td>BCLR</td>
<td>Butterworths Constitutional Law Reports</td>
</tr>
<tr>
<td>BLLR</td>
<td>Butterworths Labour Law Report</td>
</tr>
<tr>
<td>CBO</td>
<td>community based organisation</td>
</tr>
<tr>
<td>CSA</td>
<td>Centre for the Study of AIDS</td>
</tr>
<tr>
<td>CCMA</td>
<td>Commission for Conciliation, Mediation and Arbitration</td>
</tr>
<tr>
<td>DOH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>FG</td>
<td>focus group</td>
</tr>
<tr>
<td>GEAR</td>
<td>Growth, Employment and Retribution Strategy (initial economic policy of ANC-led government in 1994)</td>
</tr>
<tr>
<td>HAART</td>
<td>highly active antiretroviral treatment</td>
</tr>
<tr>
<td>HCW</td>
<td>health care worker</td>
</tr>
<tr>
<td>HIV</td>
<td>human immune deficiency syndrome</td>
</tr>
<tr>
<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
</tr>
<tr>
<td>LAC</td>
<td>Local AIDS Council</td>
</tr>
<tr>
<td>MTCT</td>
<td>mother-to-child transmission of HIV</td>
</tr>
<tr>
<td>NAPWA</td>
<td>National Association of People Living with HIV/AIDS</td>
</tr>
<tr>
<td>NCHR</td>
<td>Norwegian Centre for Human Rights</td>
</tr>
<tr>
<td>NGO</td>
<td>non-governmental organisation</td>
</tr>
<tr>
<td>PEP</td>
<td>post-exposure prophylaxis</td>
</tr>
<tr>
<td>PLHA</td>
<td>person living with HIV/AIDS</td>
</tr>
<tr>
<td>PLWA</td>
<td>person living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>prevention of mother-to-child transmission of HIV</td>
</tr>
<tr>
<td>SANAC</td>
<td>South African National AIDS Council</td>
</tr>
<tr>
<td>STD</td>
<td>sexually transmitted disease</td>
</tr>
<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
</tr>
<tr>
<td>UDHR</td>
<td>Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>voluntary counselling and testing</td>
</tr>
</tbody>
</table>
The need to “right” stigma based on HIV and AIDS (in the sense of “setting stigma right”) is much greater than the need to write about it in general terms. As others have pointed out, much has been written about stigma in the context of HIV and AIDS, but less about ways of addressing or combating stigma in such a context. Initial preoccupation to ascertain stigma has made place for efforts to explain and understand it, and eventually to find effective interventions to root out stigma.

Beyond Tswelopele

Departing from the premise that such studies are best done in a localised setting, in 2004 the Centre for the Study of AIDS (CSA), University of Pretoria, embarked on a study of stigma in two peri-urban communities around Tshwane: Hammanskraal and Temba, entitled Tswelopele (denoting “progress towards a goal” or “moving forward”). The aim was to “examine the impact of the rights-based approach to HIV/AIDS at the local level”. The Norwegian Centre for Human Rights (NCHR) was a funding and collaborative partner.

Some 140 members of the community were interviewed, either in focus groups or individually; observations were undertaken at eleven sites and follow-up (“feedback”) sessions were held with interviewees. Finding that the advent of rights in the South African Constitution has made little difference in the lives of people in these communities, the study recommends that HIV and human rights training needs to be sharpened and strengthened, and that it should especially target AIDS service organisations. The aim should be to identify and train “human rights champions” in the community as para-legals, and link them to possibilities of effective legal action. This report, drafted by the leader of the research project, Farhana Zuberi, has been published previously by the CSA (as HIV/AIDS stigma and human rights: A localised investigation of Hammanskraal communities – known as the “Tswelopele report”). It is reprinted here, as Chapter 1 of this publication.

The report summarises the research findings, and only refers to a small portion of the enormous amount of available data contained in the transcribed interviews. In an attempt to delve deeper into the data, and focus more specifically on a number of human rights-related aspects arising from the report, the CSA subsequently requested a number of people working in the field of HIV/AIDS and human rights to further explore the implications of the report. They each wrote a paper (or monograph), which was then submitted to an expert review panel for its comments. These “explorations” are now published. Although some contributions (Alexander and Mbali) go beyond exploring the data, by critically analysing aspects of the methodology of the Tswelopele study, these views are included here in the interest of ongoing debate about the issues raised.
A rights-based approach

Why is the attention here on human rights? What is the (potential) benefit of a rights-based approach in addressing stigma?

A rights-based approach stands in opposition to a policy-based approach. While the application of policy depends on the discretion of the executive, rights provided for constitutionally or in legislation enable individuals and groups to test executive action or to challenge executive inaction. Rights-based approaches rely on justiciable rights – claims about the infringement of subjective entitlements that may be decided in judicial settings, allowing for redress in the form of remedial relief. Rights-based challenges may be made against executive conduct (ostensibly) undertaken under legislation, and against the legislation itself. This approach may be directed against isolated events (for example when a health care worker unlawfully discloses someone’s HIV status), or may be directed at more far-reaching or structural problems (such as delays in implementing a treatment programme, as illustrated in the case of Minister of Health v Treatment Action Campaign). Beyond courtrooms, awareness of rights and rights victories may invigorate public participation, advocacy and, if needs be, protest and struggle.

Stigma is often implicit, living in the mind, thus making its presence difficult to establish. Sometimes it makes itself visible in subtle ways, in hints and gestures that are in need of interpretation. In its extreme form, it reveals itself as discrimination and even violence. In so far as legal responses to stigma are concerned (providing for “rights” on which claims may be based), it is useful to distinguish between actions (or omissions, in the sense of non-actions, also referred to as enacted stigma) resulting from stigma, expressions of stigma (orally, or in writing) and stigma as attitude (ideology and forming part of underlying beliefs).

Legal strategies may be and have been devised to deal with stigma at these three levels, and the rights-based framework in respect of each is now discussed in turn.

Stigma as actions

Actions resulting from stigma often amount to discrimination. In the Hoffmann case, the Constitutional Court articulated the role of stigma, especially in the workplace, as follows:

The impact of discrimination on HIV-positive people is devastating. It is even more so when it occurs in the context of employment. It denies them the right to earn a living. For this reason, they enjoy special protection in our law.

To curb discrimination generally, the Constitution expressly states that neither the state nor any individual or private entity may for any reason discriminate “unfairly” against anyone. If discrimination is alleged to have taken place on one of the specified grounds (such as race, sex and gender), the discrimination is presumed to have been “unfair”. If discrimination is alleged on any other non-specified ground, the unfairness has to be proved. Although HIV or AIDS is not included as a specific ground for non-discrimination, the Hoffmann case makes it clear that discrimination on the basis of HIV status in itself constitutes an impairment of human dignity, thus indicating that proving “unfairness” on that basis will mostly be unproblematic.

In view of the prevailing prejudice against HIV-positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity.

---

2 2005 (5) SA 721 (CC).
4 Hoffmann v SAA 2000 (11) BCLR 1211 (CC).
5 Para 28 of the Hoffmann judgment.
6 Sec 9 of the Constitution.
7 Para 28 of the Hoffmann judgment.
As its name indicates, the Promotion of Equality and Prevention of Unfair Discrimination Act (Equality Act) aims at preventing discrimination, especially on the “horizontal” level, where the state is not involved. Echoing the Constitution, HIV or AIDS is not included as a specific ground for non-discrimination. It is relegated to the “directive principles”, where the Minister must give special consideration to the possible inclusion of HIV status as a “prohibited ground” in subsequent review processes. This has so far unfortunately not been done – something that should receive attention soon.

Compared with social discrimination (for example, between neighbours), discrimination in the workplace is often more visible; it takes place in a more formal environment and is relatively easy to prove. It involves a party from whom redress (for example, in the form of reinstatement or compensation) may be successfully claimed. For these, and other reasons, governments often enact legislation protecting employees from discrimination in the workplace. In South Africa, the Employment Equity Act provides explicitly that no person may discriminate against an employee “in any employment policy or practice” on the basis of, amongst others, “HIV status”.

HIV testing without the explicit permission of the Labour Court is prohibited. The Labour Court may only permit HIV testing if testing is justifiable in the light of “medical facts, employment conditions, social policy, the fair distribution of employee benefits or the inherent requirements of a job”.

When stigma is enacted in ways that go beyond “mere discrimination”, leading to violence against property and person, the ordinary law (usually the criminal law) applies. HIV or AIDS stigma may lead to violence causing injury or even death on the basis of a person’s real or perceived HIV status, as was reported in the well-publicised case of Gugu Dlamini. This case illustrates the potential that HIV stigma may inhibit witnesses to come forward or police officers to investigate vigorously, impeding successful criminal prosecutions. Even when a criminal case is brought, as S v Moses illustrates, experts, lawyers, witnesses, prosecutors or even judicial officers enter the courtroom with their HIV stigma.

**Stigma as expression**

Verbal expression of stigma may lead to gossip, defamation or “hate speech”. General legal provisions make defamation a criminal offence and a cause for civil action. “Hate speech”, that is, communications that are intended to be hurtful, harmful and that promote hatred, is prohibited in the Equality Act. Although HIV or AIDS is not included as grounds on which hate speech is specifically prohibited, it is most likely that expressions of HIV or AIDS stigma will be covered under the general ambit of this provision.

**Stigma as attitude**

Addressing stigma as a pervasive ideology may be achieved by adopting a legal framework that supports the equal treatment of HIV-positive persons and those people living with AIDS. The laws referred to above, especially the Constitution, form part of this enabling environment. Many other factors, among them the

---

9 Sec 34 of Act 4 of 2000.  
12 Secs 7(1) and 50(4) of Act 55 of 1998.  
13 Sec 7(1)(b) of Act 55 of 1998.  
15 See para 2 in ch 4 below.  
16 1996 (1) SACR 701 (C) (in which Hlophe J found that the revelation of “AIDS status” (actually, HIV status) by one gay lover to the other could constitute “extreme provocation”, occasioning non-pathological criminal incapacity that could serve as a ground for acquittal on a charge of murder by the informed partner of the HIV-positive partner).  
17 Sec 10 of Act 4 of 2000.
content and quality of HIV and AIDS education and media stereotyping, also play a role in the general environment in which stigma either thrives or is weakened.

Education has an important role to play in reversing the spread of stigma. The better informed people are, the theory goes, the better they will understand that they are exposed to an uncontrolled threat, that HIV infection is a possibility that can befall anyone, and that it is not necessarily a death sentence. However, education is premised on the usefulness of rational discourses and reasoned decision-making. To a great extent though, HIV and AIDS stigma is driven by deep-seated fears and irrational prejudices. One sweep of the wand of education can obviously not change cultural roots and the structure of society. Material deprivation, occasioning for example the gendered nature of commodified sex, has to be accepted. (See Alexander and Mbali's contribution.) Indeed, as much as mind-sets matter, material conditions matter more.

Given the limitations of education and awareness-raising in turning the tide of HIV and AIDS stigma, other avenues have to be explored more rigorously. One of these is the “legal route” (or rights-based approach). Despite the possibilities that are open to communities, and the dire need for legal action, little has been done to unleash the law's potential. As the Tswelopele report emphasises, the community must be empowered through trained para-legals who are able to link the community to legal fora. For this reason (and others), the Tswelopele project will be expanded in the future. Funding has been secured for a follow-up project, Tswelopele II, which will be aimed amongst others at building capacity in the Hammanskraal and Temba communities to recognise HIV/AIDS-related human rights violations and to refer instances of violations appropriately. An example is the building of capacity of the Community Advisory Board to engage with key decision-makers in Hammanskraal, in order to raise awareness and advocate for the implementation on HIV/AIDS and human rights-related issues. Realising that education, awareness-raising and capacity-building remain insufficient to address structural and deep-seated concerns, Tswelopele II will also aim to intervene where HIV/AIDS-related human rights violations occur, by identifying trends of human rights violations in the community through an investigation of the types of cases being referred to the paralegal centre. This process should lead to test case litigation, if appropriate; and ultimately to appearances in court and other administrative tribunals if required.

**Stigma as a barrier to rights**

Each of these contributions takes a particular right in the South African Bill of Rights as starting point: section 9 – the right to equality and non-discrimination on the basis of sex and gender (Alexander and Mbali); section 14 – the right to privacy (Viljoen); section 12 – the right of freedom and security of the person (Nongogo); section 27(1)(a) – the right of access to health care services (Joni); and section 27(1)(c) – the right of access to social assistance (Zuberi). Based on the premise that the rights are available to “everyone”, the Constitution aims to permeate the values of equality, human dignity and freedom into all South African communities. As the Tswelopele study shows, HIV and AIDS stigma poses a barrier to the respect and realisation of rights. There are in any event many reasons, such as poverty, illiteracy, geographic distance, inaccessible language and perceptions about accessibility, that account for people’s inability to avail themselves of the law. Stigma arising from HIV and AIDS may pose an additional impediment to access. Even those in relatively privileged positions may as a consequence be excluded. For those already living at the law’s margins, HIV or AIDS stigma places one more – significant – burden impeding access to justice. The result is that those most in need of the law’s safeguards and support are exposed to an increased multiplicity of exclusion.

The contributions of Viljoen and Joni deal with stigma-related impediments to accessing health care services. As the study was conducted in a context where access
to antiretroviral drugs (ARVs) was very limited if not non-existent, the question is left open whether access to life-sustaining medications will reduce stigma – either for the individual who benefits, or collectively for all that have AIDS.\textsuperscript{18} What seems to be clear is that health care workers are themselves in no way free from stigma. In fact, they may often be the first line of assault a person living with HIV has to face. Accessing social services may sometimes require the disclosure of facts that could lead to stigmatisation, for instance when applying for a disability grant. Fear of stigma or internalised stigma may thus impede access to available social assistance.

In her contribution, Zuberi shows that the use by HIV-positive people of these services may in themselves be an additional stigmatising factor, feeding into people’s prejudices, adding the dimension of alleged devious and deliberate infection in order to procure undeserved benefits. Nongogo deals with the challenges to expand voluntary and fully informed HIV testing, and the role stigma plays.

Calls for routine HIV testing (some argue, a routine offer without prior counselling of an HIV test for all patients presenting themselves – for whatever reason – at health services) are made increasingly. One of the arguments is that openness about HIV will turn it into an acceptable, commonplace – and non-stigmatised – disease. However, such contentions have to be rejected in societies where prevailing levels of stigma are as high as they are in the Hammanskraal area. In such contexts, the introduction of routine HIV testing would necessarily be premised on the utilitarian tenet that the greater good (destigmatisation) is served only through, and outweighs, the sacrifice of the few (those HIV-positive persons who suffer the brunt of immediate stigma as a result of being tested).

The contributions in this collection concentrate mainly on the role of the law and of rights, but it should be kept in mind that the law forms part of the political ordering of society, and functions against the background of social realities. There are many other interventions that may result in destigmatisation, such as the mobilising of people living with HIV and AIDS. However, the potential of the rights-based approach as one possible intervention in addressing HIV/AIDS stigma has thus far been neglected. This publication is an attempt to find footpaths that could mark significant progress on the road towards the goal of greater human dignity, tolerance and acceptance.

Acknowledgements

I gladly acknowledge the assistance of the following: Farhana Zuberi (who oversaw the initial research project), Mary Crewe and Pierre Brouard (who initiated and guided the process), the Norwegian Centre for Human Rights (that funded the project), Robin Hamilton (who did an initial edit for language and style), Rakhadi Mohlahlana and Tiny Mdlalose (who acted as members of the expert review panel), Jimmy Pieterse (who traced references and collated the reviewers’ comments), Johan Maritz (who identified suitable photographs), Musa Njoko (for the permission to use her image for the title page of Chapter 3), as well as Susan Precious and Lily Grainger (who carefully and insightfully read the manuscript).

\textsuperscript{18} One should be reminded, though, of the following remark of the Constitutional Court in the Hoffmann case (para 28): “People who are living with HIV/AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence as to how this disease is transmitted, the prejudices and stereotypes against HIV-positive people still persist.”
CHAPTER 1

“If you (be)come HIV positive, you will lose your human rights.”

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 AIDS¹

Farhana Zuberi
Consultant, Centre for the Study of AIDS, University of Pretoria

¹ This is a reprint of the report that was previously published by the CSA, and is available at www.csa.up.za.org. Appendices 1 and 2 of the original report, which contain a full demographic profile of the focus groups, are omitted here. Full transcripts of all interviews are available from the CSA.
* E-mail farhanazuberi@hotmail.com.
1. Introduction

The link between HIV/AIDS and human rights became apparent early on in the HIV/AIDS epidemic through the increased vulnerability of infection of some groups. HIV/AIDS is a human rights issue because groups that are already vulnerable to human rights violations – such as women, children, sex workers, and those living in poverty – are unable to realise their rights. This makes them more susceptible to HIV/AIDS.

Individuals who are denied the right to freedom of association and access to information may be precluded from discussing issues related to HIV/AIDS, participating in AIDS service organisations and self-help groups, and taking other preventive measures to protect themselves from HIV infection. For example, women, and particularly young women, are more vulnerable to infection if they lack access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. People living in poverty are often unable to access HIV care and treatment, including antiretroviral treatment and medication for opportunistic infections. Thus, we see that in Africa, AIDS as a disease is particularly destructive for young black women.

The rights of people living with HIV/AIDS are often violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the burden of discrimination. Stigmatisation and discrimination may affect uptake of treatment, and may also affect employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services.

2. A Rights-based Approach

2.1 What is a (human) rights-based approach to HIV/AIDS?

A rights-based approach to HIV/AIDS means locating the needs of those infected and affected by HIV/AIDS in a human rights context, so that rights can be claimed and asserted. It is a movement away from policy, which is usually at the discretion of government and other policymakers, towards mechanisms whereby rights can be translated into practice, and given status and recognition in international and domestic law. As such, the rights-based approach has the potential to be a powerful and empowering tool.

The promotion and protection of human rights reduces vulnerability to HIV infection by addressing its root causes, lessening the adverse impact on those infected and affected by HIV, and empowering individuals and communities to respond to the pandemic.

States’ obligations to promote and protect HIV/AIDS-related human rights are defined in existing international treaties and include, amongst others: the right to life;...
the right to liberty and security of the person; the right to the highest attainable standard of mental and physical health; the right to non-discrimination, equal protection and equality before the law; the right to freedom of movement; the right to seek and enjoy asylum; the right to privacy; the right to freedom of expression and opinion and the right to freely receive and impart information; the right to freedom of association; the right to marry and to found a family; the right to work; the right to equal access to education; the right to an adequate standard of living; the right to social security, assistance and welfare; the right to share in scientific advancement and its benefits; the right to participate in public and cultural life; and the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.

Recognising the importance of 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, developed in consultation by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Office of the United Nations High Commissioner for Human Rights, with input from various stakeholders in the private and public sectors (including NGOs, CBOs, academics, people living with HIV/AIDS, etc.), and the United Nations General Assembly Special Session Declaration (UNGASS Declaration) which recognised that stigma, silence, discrimination, denial and a lack of confidentiality undermine efforts to curb the spread and the treatment of HIV/AIDS, and impact negatively on individuals, families, communities and nations.

Studies have shown that common human rights violations associated with HIV/AIDS include:

- lack of access to health care services or proper treatment, including disclosure of HIV status by health care workers without consent, and HIV testing without informed consent,
- violation of human dignity, often through the actions of family and community, and
- gender rights violations especially related to the treatment of women by their partners and their in-laws.

### 2.2 HIV/AIDS and human rights in South Africa

At national level, South Africa has responded to human rights challenges in a variety of ways. South Africa has ratified or signed the following international and regional legal human rights instruments:

#### International instruments

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Date ratified</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Covenant on Economic, Social and Cultural Rights (ICESCR)</td>
<td>3 October 1994 (signed)</td>
</tr>
<tr>
<td>International Covenant on Civil and Political Rights (ICCPR)</td>
<td>10 March 1999</td>
</tr>
<tr>
<td>ICCPR First Optional Protocol</td>
<td>28 August 2002</td>
</tr>
<tr>
<td>ICCPR Second Optional Protocol</td>
<td>28 August 2002</td>
</tr>
<tr>
<td>Convention on the Elimination of All Forms of Racial Discrimination (CERD)</td>
<td>9 January 1999</td>
</tr>
<tr>
<td>Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)</td>
<td>14 January 1996</td>
</tr>
</tbody>
</table>

---

9 Current as at 9 June 2004.
Regional instruments

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Date ratified</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Charter on Human and Peoples' Rights (ACHPR)</td>
<td>9 July 1996</td>
</tr>
<tr>
<td>African Charter on the Rights and Welfare of the Child (ACRWC)</td>
<td>7 January 2000</td>
</tr>
</tbody>
</table>

Constitutional rights

Furthermore, the Bill of Rights, Chapter 2 of the Constitution, lists important rights that all people have. People must respect, protect, promote and fulfil these rights. These rights include:

- 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
- environment
- access to housing
- access to health care, food, water and social security, and
- access to information.

These rights are important because they protect people from being treated unfairly and discriminated against. These rights apply equally to all people living in South Africa, including those living with HIV and AIDS.

In South Africa, the scope and nature of human rights violations involving HIV/AIDS can be shown through the changing emphasis of the work of the AIDS Law Project. Of 290 cases handled by the AIDS Law Project (ALP) between 1993 and 2000, the major distribution of cases, as calculated by Richter (2001), was as follows: 24% dealt with issues to do with "medical testing"; 23% with "employer discrimination" and 10% with "insurance". A further 23% were placed in the category "other", and included death certificates, harassment and so on. Tracking the changes over these years, Richter suggests that the ALP’s work reflected a more general shift in discrimination. Whereas initially the focus was on getting persons living with AIDS (PLWAs) “into spheres where they were excluded like the workplace, the medical aid and insurance industry”, following legislative and policy changes, “energies were [then] directed at obtaining the same benefits and privileges for PLWAs that other people were entitled to in those same areas”.

More recently there has been a highly visible emphasis upon the right to health, including treatment for HIV/AIDS. In South Africa, the debate has culminated in the government announcing plans in August 2003 to provide free antiretroviral treatment (ART) at public hospitals to those who need it. In November 2003, the government tabled its policy for the implementation of ART. There has been some concern about the length of time that

11 Ibid.
implementation of the policy has taken, and the Treatment Action Campaign, after co-operating with the government and offering assistance for implementation, has been threatening to take the matter to court to ensure that the policy is implemented in a timeous manner.

Other areas of interest and public debate in HIV/AIDS in South Africa at present include: shared confidentiality, the need to inform partners and others at risk of the individual’s HIV status, discrimination against employees such as domestic workers, and HIV-positive children in pre-schools.\(^{12}\)

Initiatives by the South African government include the provisions in the \textit{HIV/AIDS/STD Strategic Plan for South Africa 2000-2005}, which identifies human and legal rights as a priority issue. The HIV/AIDS Directorate has appointed a human and legal rights officer to develop the priority area further. The goals are to create a culture of openness and acceptance regarding HIV/AIDS and STDs, to ensure that the rights of people living with AIDS are protected, and to develop mechanisms to assist people living with AIDS to enforce their rights.

However, it is important to note that most of these studies and initiatives target urban areas in South Africa. One motivating force is therefore to identify the scope and nature of human rights violations in a specific community and area that can be classified as peri-urban and rural.

3. The Tswelopele Study

3.1 The purpose of the study

While much has been done and documented at global and national levels, there is little information on the impact of the human rights approach on local communities. In the words of Dr Peter Piot, Executive Director of UNAIDS:\(^{13}\)

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 purpose of this study, therefore, is to examine the impact of the rights-based approach to HIV/AIDS at local level. Importantly, this study will attempt to determine if, and to what extent, the human rights approach has been localised; 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 will also ask if the ideals contained in the Constitution, the \textit{International Guidelines} and the \textit{National Strategy} have permeated to local community level. At the outset, in view of the obvious resilience and complexity of stigma as a major factor leading to human rights violations, the project sought to dissect the anatomy of stigma.

3.2 Study objectives

The objectives of the Tswelopele Project were:

1. To attempt to clarify how the process of HIV/AIDS stigmatisation and concomitant discrimination plays itself out in a traditional setting in South Africa, including an examination of how stigma is manifested and what consequences such stigmatisation has on local community members. The project looked at which human rights were consequently violated or otherwise compromised.


\(^{13}\) As quoted in the Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa (AMICAALL), to which South Africa belongs. AMICAALL recognises the need for action at the local level, and the vital role that is to be played by municipalities. It acknowledges that “national government officials may be too far away to hear voice of ordinary citizens ...” Local problems need local efforts to resolve them, and the greatest impact of the epidemic is felt in communities. For more information, refer to the AMICAALL website www.amicaall.org.
2. To establish which organisations and institutions were playing a role in the promotion of human rights at local level, the role of democratically elected representatives and traditional leaders, and whether PLHAs were playing a role in governance at this level. The research examined whether a culture of human rights had been absorbed into governance at the local level and whether, what and where support was being provided.

3. To examine the impact, or lack thereof, of the human rights discourse on individuals, families and communities, including why individuals were, or were not, enforcing their rights or using the services provided for them. It also tried to determine whether the rights-based approach led to community activism and empowerment, and why this had, or had not, occurred. It examined whether or not people living with HIV/AIDS (PLHAs) viewed the human rights discourse as helpful, i.e. whether the ‘insertion’ of human rights in itself was helpful or problematic in overcoming stigma and discrimination.

4. To examine the impact of the human rights discourse on service delivery in the health sector, if any, and the linkages to the government’s Batho Pele campaign and other initiatives focused on patients’ rights. The research looked at whether there was a place for a human rights perspective in these ventures and what opportunities there were for intervention to reduce HIV/AIDS stigma in the health sector.

5. Finally, the goal of the research was to offer recommendations on how best to increase accessibility to, and use of, human rights support services and programmes at the local level, and to enhance service delivery in various sectors such as health services. An important component of the study was the development of a training manual to improve human rights literacy, similar to the one developed by the Asia Pacific Council of AIDS Service Organisations (APCASO) and entitled *HIV/AIDS and Human Rights: A Training Manual for NGOs, Community Groups and People Living with HIV/AIDS*.

### 3.3 Methodology

#### 3.3.1 Research site

The selected site for the research was the Hammanskraal and Temba area of Tshwane Municipality.

There were various reasons for the selection of the Hammanskraal/Temb area as the research site. Hammanskraal and Temba are a complex mix of rural and peri-urban communities. Under the new demarcation, the areas of Hammanskraal and Temba fall within the Tshwane Municipality, a Category A municipality with no district (Category C) municipality overlaying the area. However, the area is also cross-provincial, falling within both the Gauteng and North West Provinces, creating a situation of an overlap in area for various services, including health and education. Thus, the Tshwane Municipality and the Moretele Local Municipality (Category B Municipality, with Bojanala District Municipality the Category C Municipality overlaying it) are involved in service delivery in the area. Further, while there is an elected local council, there are also tribal authorities that are still prominent in the areas.

There are approximately 24 organisations providing a range of HIV/AIDS services, excluding research. These

---

14 The Batho Pele campaign is effectively a service delivery campaign aimed at public servants with eight key principles of service delivery: consultation, service standards, access, courtesy, information, openness and transparency, redress and value for money. The Batho Pele campaign was launched in 1998 and staff have been trained in the principles. Individual clinics have translated the principles into local languages and posters are displayed in clinics. The Batho Pele White Paper can be found at www.info.gov.za/whitepaper/1997/18340.pdf.

15 A Courtesy Charter was also launched, as was a Patient’s Rights Charter in 2001.

16 Available at apcaso@pd.jaring.my.

include governmental, non-governmental and community-based organisations. The area has 26 primary health clinics and two mobile health clinics, six clinics offer Nevirapine as part of the government prevention of mother-to-child transmission (PMTCT) programme, and 16 clinics offer voluntary counselling and testing (VCT) services. The hospital in the area is Jubilee Hospital, which also offers VCT and PMTCT services, but has not been selected as a site for the ARV roll-out in the North West Province.

Despite the number of services available, and the fact that there are two provinces involved in service delivery, effective service delivery is limited. In general, resources are clustered in Temba and there is a need for a greater spread of services. In addition, although there have been HIV/AIDS initiatives within the community and other sectors, there is little or no coordination of these activities.

The Centre for the Study of AIDS and the University of Pretoria have a number of links with the Hammanskraal area. Hammanskraal is one of three satellite campuses maintained by the University. Through its Satellite Office, the Centre for the Study of AIDS has excellent contacts with the community and is familiar with the surrounding geography. Hammanskraal is also a short driving distance from Pretoria, which assisted in communication and supervision of the project.

3.3.2 Research team

The research team consisted of the primary researcher/coordinator and an assistant researcher. The assistant researcher was fluent in several South African languages, including Sesotho and Setswana, and conducted the focus group discussions in these languages.

The research team was supplemented by the researcher of the South Africa Programme of the Norwegian Centre for Human Rights. His assistance included, but was not limited to: maintaining the overall vision of the project; offering human rights input; advising on methods and methodology; and assisting with some fieldwork.

3.3.3 Research design

3.3.3.1 Situation analysis

The first phase of the research design involved a situation analysis. This was carried out in January 2004, and examined existing structures, including the public hospital in the area, Jubilee Hospital, primary health clinics, schools, churches, AIDS service organisations and NGOs in the area. The report also provided socio-economic information on the population.

Based on the outcome of the situation analysis, a schedule was drawn up highlighting the different groups and stakeholders in the community that should form part of the research, either through focus groups, key informant interviews or observation. Given the nature of the enquiry and the absence of relevant sampling frames that could lead to random sampling, no attempt was made to utilise more representative forms of sampling.

Interview schedules were developed for use in the data collection phase of the project.

3.3.3.2 Data collection

Data collection was undertaken from February to May 2004. The primary approach to data collection utilised focus group discussions and key informant interviews with PLHAs and others from the community, such as members of social clubs, youth groups, etc. Observation was undertaken in health care settings such as hospitals, clinics and other government service delivery points.

---

18 The January 2004 Situation analysis: human rights and HIV/AIDS in Hammanskraal and Temba is available from the Centre for the Study of AIDS.
Focus groups

A total of 15 focus groups with key local stakeholders were held, comprising 116 people. The groups ranged from 4 to 15 persons. The focus groups were primarily conducted in Setswana or Sesotho. A translator/transcriber was identified and all discussions were transcribed into English for analysis.

The focus groups conducted during the data collection phase were as follows:

<table>
<thead>
<tr>
<th>Number</th>
<th>Group</th>
<th>Number of focus groups held</th>
<th>Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>FG1</td>
<td>PLHAs</td>
<td>4</td>
<td>28 February 2004</td>
</tr>
<tr>
<td>FG2</td>
<td></td>
<td></td>
<td>15 March 2004</td>
</tr>
<tr>
<td>FG3</td>
<td></td>
<td></td>
<td>29 March 2004</td>
</tr>
<tr>
<td>FG4</td>
<td></td>
<td></td>
<td>19 April 2004</td>
</tr>
<tr>
<td>FG5</td>
<td>Health-care workers</td>
<td>3</td>
<td>10 May 2004</td>
</tr>
<tr>
<td>FG6</td>
<td></td>
<td></td>
<td>20 May 2004</td>
</tr>
<tr>
<td>FG7</td>
<td></td>
<td></td>
<td>22 May 2004</td>
</tr>
<tr>
<td>FG8</td>
<td>Social clubs</td>
<td>2 women's groups</td>
<td>Women's groups:</td>
</tr>
<tr>
<td>FG9</td>
<td></td>
<td>1 men's group</td>
<td>27 March 2004</td>
</tr>
<tr>
<td>FG10</td>
<td></td>
<td></td>
<td>27 March 2004</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Men's group:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>17 April 2004</td>
</tr>
<tr>
<td>FG11</td>
<td>Youth clubs</td>
<td>3</td>
<td>3 April 2004</td>
</tr>
<tr>
<td>FG12</td>
<td></td>
<td></td>
<td>3 April 2004</td>
</tr>
<tr>
<td>FG13</td>
<td></td>
<td></td>
<td>17 April 2004</td>
</tr>
<tr>
<td>FG14</td>
<td>Police services</td>
<td>1</td>
<td>4 May 2004</td>
</tr>
<tr>
<td>FG15</td>
<td>Local government councillors</td>
<td>1</td>
<td>14 May 2004</td>
</tr>
</tbody>
</table>

For a full demographic profile of the focus groups, refer to Appendix 2 in the original report.

Key informant interviews

A total of 23 key informant interviews were conducted. The key informant interviews were conducted primarily in English, although respondents were encouraged to answer in any language in which they felt comfortable. Notes of all interviews are available, and selected interviews were transcribed in full.
The following key informant interviews were conducted:

<table>
<thead>
<tr>
<th>Number</th>
<th>Key informant interviewed</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>KI1</td>
<td>Hammanskraal Legal Aid Clinic director</td>
<td>27 February 2004</td>
</tr>
<tr>
<td>KI2</td>
<td>Chair of Local AIDS Council</td>
<td>1 March 2004</td>
</tr>
<tr>
<td>KI3</td>
<td>District health promotion officer</td>
<td>1 March 2004</td>
</tr>
<tr>
<td>KI4</td>
<td>Representative of South African National Civics Organisation (SANCO)</td>
<td>1 March 2004</td>
</tr>
<tr>
<td>KI5</td>
<td>Director, Aganang Community Development Centre</td>
<td>1 March 2004</td>
</tr>
<tr>
<td>KI6</td>
<td>Pastor</td>
<td>2 March 2004</td>
</tr>
<tr>
<td>KI7</td>
<td>Sangoma and assistant/son</td>
<td>2 March 2004</td>
</tr>
<tr>
<td>KI8</td>
<td>Representative of Funeral Services Company</td>
<td>2 March 2004</td>
</tr>
<tr>
<td>KI9</td>
<td>Director, Sakha Ubuntu</td>
<td>8 March 2004</td>
</tr>
<tr>
<td>KI10</td>
<td>Director, PRUDEC</td>
<td>11 March 2004</td>
</tr>
<tr>
<td>KI11</td>
<td>Coordinator for Hammanskraal, AIDS Unit of Tshwane Municipality</td>
<td>25 April 2004</td>
</tr>
<tr>
<td>KI12</td>
<td>Community liaison officer, Department of Social Services, Arts, Culture and Sport, North West Province</td>
<td>29 April 2004</td>
</tr>
<tr>
<td>KI13</td>
<td>Community events radio presenter</td>
<td>29 April 2004</td>
</tr>
<tr>
<td>KI14</td>
<td>Assistant director, Community Health Services, District Department of Health</td>
<td>4 May 2004</td>
</tr>
<tr>
<td>KI15</td>
<td>Clinic doctor</td>
<td>4 May 2004</td>
</tr>
<tr>
<td>KI16</td>
<td>Lay preacher</td>
<td>8 May 2004</td>
</tr>
<tr>
<td>KI17</td>
<td>Director, Tshwane Youth Development (NGO)</td>
<td>8 May 2004</td>
</tr>
<tr>
<td>KI18</td>
<td>Assistant director, Administration, District Department of Health</td>
<td>10 May 2004</td>
</tr>
<tr>
<td>KI19</td>
<td>Traditional leader</td>
<td>11 May 2004</td>
</tr>
<tr>
<td>KI20</td>
<td>Candidate attorney from law clinic</td>
<td>11 May 2004</td>
</tr>
<tr>
<td>KI21</td>
<td>Social worker, Department of Social Services, Arts, Culture and Sport, North West Province</td>
<td>13 May 2004</td>
</tr>
<tr>
<td>KI22</td>
<td>Senior administration clerk, Department of Home Affairs</td>
<td>20 May 2004</td>
</tr>
<tr>
<td>KI23</td>
<td>Teacher</td>
<td>22 May 2004</td>
</tr>
</tbody>
</table>

Observation

Observation was undertaken at 11 sites, comprising primary health clinics, Jubilee Hospital, and other government delivery points.
Observation was undertaken at various sites, including:

<table>
<thead>
<tr>
<th>Number</th>
<th>Site visited</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Local AIDS Council Executive Committee Meeting</td>
<td>8 March 2004</td>
</tr>
<tr>
<td>2</td>
<td>Local AIDS Council Meeting</td>
<td>11 March 2004</td>
</tr>
<tr>
<td>3</td>
<td>Jubilee Hospital, Room 6 (VCT for in-patients)</td>
<td>29 April 2004</td>
</tr>
<tr>
<td>4</td>
<td>Magistrate’s Court</td>
<td>29 April 2004</td>
</tr>
<tr>
<td>5</td>
<td>Local Department of Home Affairs</td>
<td>29 April 2004</td>
</tr>
<tr>
<td>6</td>
<td>Mathibistad Clinic</td>
<td>14 May 2004</td>
</tr>
<tr>
<td>7</td>
<td>Kekanastad Clinic</td>
<td>14 May 2004</td>
</tr>
<tr>
<td>8</td>
<td>Moretele Youth Clinic</td>
<td>14 May 2004</td>
</tr>
<tr>
<td>9</td>
<td>Dirtag Clinic</td>
<td>14 May 2004</td>
</tr>
<tr>
<td>10</td>
<td>Jubilee Hospital – Step Down Ward</td>
<td>20 May 2004</td>
</tr>
</tbody>
</table>

For a full list of focus groups, key informant interviews and observation sites, refer to Appendix 1 of the original report.

3.3.3.3 Feedback sessions

Data collation and analysis was undertaken from June to August 2004 and a draft report was prepared. Feedback workshops were held in Hammanskraal in September 2004 to obtain community feedback into the findings. The following feedback sessions were conducted:

<table>
<thead>
<tr>
<th>Number</th>
<th>Feedback group</th>
<th>Number of people</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>FB1</td>
<td>Youth groups</td>
<td>8: 6 M, 2 F. Two had not participated in original research.</td>
<td>4 September 2004</td>
</tr>
<tr>
<td>FB2</td>
<td>Social clubs</td>
<td>10: 6 M, 4 F. All had been part of initial research.</td>
<td>4 September 2004</td>
</tr>
<tr>
<td>FB3</td>
<td>People living with HIV and AIDS</td>
<td>12: 2 M, 10 F. Seven were not part of original research.</td>
<td>9 September 2004</td>
</tr>
<tr>
<td>FB4</td>
<td>General feedback session</td>
<td>32: 10 M, 22 F. Eight had not been part of original research.</td>
<td>20 September 2004</td>
</tr>
</tbody>
</table>

3.3.3.4 Potential limitations/problems of research

There are various limitations to the research that must be borne in mind, and that may have had an impact on
the findings of the research, and these are discussed briefly below:

- The stipend provided for the research participants could be problematic, as it is unclear whether people participated in the study and/or providing answers simply for the payment. In this community, where many people are unemployed or survive on government grants, the stipend may have been even more of an issue and this point should be noted. Although perhaps this acted as a motivation to attend the focus group, there was little evidence that this affected views or responses.

- There is a difficulty in accessing PLHAs, which is naturally related to the issues of confidentiality and disclosure. For this study, all PLHAs were accessed through the local hospice, and although they may not have disclosed publicly, they had undergone training and capacity building at the hospice to deal with issues related to HIV/AIDS. This may have impacted on the answers in the focus group discussions. While an attempt was made to access other, non-hospice-aligned PLHAs, this was not successful. This highlights the role that support groups and structures play in the lives of PLHAs.

- When accessing government employees such as health care workers or officials for focus groups discussions and key informant interviews, permission had to be sought from administration. While people were assured of the confidentiality of their answers, they may have felt constrained to answer honestly. They may have felt they were expected, implicitly or explicitly, to stress the policy objectives of their employers. The same can be said for observation at health care institutions.

- The focus groups were not deliberately disaggregated by sex, although this did naturally occur at times, and this may have influenced the answers given during the groups. Further, the race and gender of the researchers (one African male, one Indian female) may have impacted on the focus groups and key informant interviews. Other potential methodological issues concerning focus groups involve the group dynamics and whether particular individuals dominate discussions. Again, the group facilitators in all cases were conscious of incorporating a broad spectrum of responses. Although focus groups by their nature depend on group dynamics they nonetheless have been shown to be a highly effective method for generating “knowledge in situ”. In other words the production of knowledge in the various focus groups corresponded to how individuals construct their knowledge of issues in social settings, i.e. with others.

- Capturing people’s discriminatory attitudes is difficult. There is a significant difference between responses when people are asked individually, as opposed to in a group setting. Cognisant of this fact, members of focus groups were not asked directly about stigma, nor were they pressed on the way that they treated people with HIV/AIDS. It is clear that most, if not all, people would not admit that they discriminated against people with HIV/AIDS. The focus groups, especially those in the social and youth clubs, highlighted that while members in the community treated people living with HIV or AIDS badly, the members of the group said they did not do so, but rather treated everyone equally. This was echoed by health care workers, who said that they treated all people equally, whether HIV positive or not, which is in direct contrast to the treatment that PLHAs say they receive when visiting health care institutions.

19 This is perhaps in contrast to the AID Law Project’s recent study on discrimination and stigma (2003), which tended to deal with the question of discriminatory attitudes individually, reflected in perhaps a tendency for people to deny having discriminatory attitudes. In a group setting this is perhaps harder to do, with these group dynamics revealing prevailing social norms. See Discrimination and HIV/AIDS by Mark Heywood and Marlise Richter of the AIDS Law Project and Ross Jennings, Jowie Mulaudzi and David Everatt (Strategy and Tactics). See also Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector, Pan American Organisation, 2003, for more information on the difficulties of “measuring” stigma.
• While no conscious effort was made by the researchers to focus on one racial group, the focus group discus-sants were all African. The key informant interviews were primarily with Africans, with few exceptions. The researchers believe that this is due to the population and other dynamics in the Hammanskraal and Temba areas, rather than for any other reason.

• Finally, as other researchers have noted, it is not possible to determine with certainty what people perceive and what their real experiences of stigma and discrimination are. This has been well documented in various studies on stigma and discrimination.20

Due to the small sample size and the fact that the research did not undertake random sampling, the research cannot be generalised to all communities of South Africa. However, the findings are indicative and provide a very useful insight into HIV/AIDS and human rights in peri-urban communities throughout South Africa.

4. Key Findings

4.1 Introduction

The key findings from the research will be discussed under the following headings:

1. Stigmatisation. As many authors have indicated, stigma is a complex process involving interrelated concepts. Stigma is affected by the gender/class/race dynamics in a particular context. In order to dissect ‘stigma’, we deconstructed it into the following sub-categories:

• labelling of physical differences
• linking differences with negative attributes
• separating “us” from “them”
• “gossiping” and community dynamics as vehicles to achieve many of these other elements, and
• gender relations.

It is important to note that these sub-categories often occur simultaneously and in various combinations in any given context.

2. Possible reasons for stigmatisation, i.e. lack of knowledge and ignorance, and the fear of having other people find out about HIV status.

3. Human rights violations, i.e. the consequences of stigmatisation, and what form they take at the community level, including issues about:

• privacy and disclosure
• informed consent and HIV testing, and
• access to health care services.

4. Other human rights issues:

• access to social security, and
• the rights of orphans and vulnerable children.

5. Tackling stigma and human rights violations: the roles of various stakeholders in the community:

• family
• faith-based organisations
• the police
• health care workers
• traditional healers
• local government, including the Local AIDS Council (LAC), and
• others dealing with human rights violations.

Based on the findings of the study, an analysis will follow on the impact of a rights-based approach at local level.

20 For information on stigma and discrimination, please refer to the Centre for the Study of AIDS, Siyam’kela project, available at www.csa.za.org.
4.2 The process of stigmatisation

In general, the levels of understanding of stigma and understanding of the effects of it are high in both PLHA and non-PLHA groups. People are able to recognise the process of stigmatisation and the impact on a person who is HIV positive.

4.2.1 Labelling physical differences

So when they see a person who is HIV positive they think that this person has no virus, because they believe that if you are HIV positive you have to be very ill, they have to see the symptoms, they want to see you losing weight, then they will be convinced that you are ill, you see. But when they see you moving around, they will say you are playing games with them, you are not ill; you are getting paid to talk like that.

– Male PLHA, FG1

They said, ‘Are you really infected? You look beautiful’.

– Female PLHA, FG3

Being thin, they can see you when you are thin.

– Female PLHA, FG3

They will say, ‘Have you seen her? Her hair has fallen off. You know she had hips but now they are no more there’.

– Female PLHA, FG4

A person would lose weight and they would start saying ... no, in the past before HIV/AIDS was there, people would say that the person is struggling, you know, the person is not happy. But these days, when a person loses weight, then they would gossip about that and the worst is that even the literate, the very educators would gossip about one educator, whether an educator is suffering from flu, they would say HIV and AIDS has started.

– Teacher, KI23

When asked about the physical manifestations of HIV or AIDS, and whether it was possible to identify whether someone had HIV/AIDS by looking at them, there was a wide variety of answers. While in the past, a loss of weight could be ascribed to various factors such as stress or another illness, now it was directly related to HIV/AIDS (FG3).

The PHAs were the best informed on the physical manifestations of HIV/AIDS, and answered that it was not possible to identify a person who was HIV positive without seeing the results of a test. However, the focus on weight loss as a symptom of HIV/AIDS came out clearly in the focus groups with PLHAs. PLHAs, especially the women, stating that there was almost an obsession with weight in the community; as soon as a person lost weight, it was deemed to be due to his/her HIV status. If a woman gained weight, on the other hand, she was deemed to be pregnant.

Weight loss was also deemed an important symptom by the members of the women’s social clubs (FG8 and FG9), male social club (FG10), and youth groups (FG11, FG12, and FG13), and in several key informant interviews (KI6, KI9, KI13, KI14, and KI17). Many of the focus groups mentioned “Bio-slim” as a term used to refer to someone with HIV/AIDS. Bio-slim is a product that used to achieve weight loss (Female PLHA, FG3; Male PLHA, FG4; FG8, FG9).

21 There have been numerous examinations of HIV/AIDS and stigma, and these will not be discussed in detail in this report. For example, please refer to Siyam’kela: Measuring HIV/AIDS-related stigma literature review, available at www.csa.za.org. The analysis of stigma is loosely based on Link and Phelan’s five components of stigmatisation. See “Conceptualizing Stigma” (2001) 27 Annual Review of Sociology 363-385. However, we have added components to explain the issues that arose during the research.
Other physical attributes that were perceived to be symptoms of HIV/AIDS were: coughing (FG9, FG14), hair falling out, lips changing to red and eyes bright and bulging, body sores (FG14); throbbing veins (KI7); changes in complexion (K116); yellow spots on the head; and pimples (FG11).

The converse, therefore, was that people did not believe that one could be HIV positive and still be healthy (Male, FG1). PLHAs described incidents in which community members did not believe that they were positive, and said that they must be getting paid to say that they were HIV positive (Female PLHA, FG2). One PLHA described being told that her body would give in and she would become tiny and thin like an infant (FG1), indicating a lack of knowledge about the progression of HIV to AIDS. Another PLHA recalled a story where a doctor pointed to her swollen lymph glands at a funeral and told others that she looked like she had HIV. This was enough to start gossip about her status (FG2).

Once labelled as HIV positive, whether or not it was true, the person was ostracised. HIV was associated with negative attributes/behaviours. The gossiping that ensued was an intrusive process that eroded the person’s self-esteem. Sometimes a person would withdraw from social situations to protect himself/herself from the gossiping (such as from a burial club (Female PLHA, FG3); work (Female PLHA, FG4); a social club (Female PLHA, FG4); and participating in food preparation for a funeral (FG2, FG3, FG4, FG8, FG9)).

4.2.2 Linking HIV/AIDS with negative attributes

4.2.2.1 Death

People told themselves that if you are HIV positive that means that you are awaiting your death. That is why they don’t respect you if you are HIV positive. They just think you are going to die.
– Male PLHA, FG1

The problem is that people are afraid of death, so it’s difficult to deal with death. The only thing that I will do is to tell people that ‘Hey, this disease kills’, and don’t tell them you are not going to die now, there is a period between death and that disease. So if the explanation was put like that it would have been better. So they just said if you have the disease that means your death.
– Male PLHA, FG1

I think people are scared of HIV/AIDS because it doesn’t have any cure. So immediately when people are diagnosed with it, they have their death in their minds. A person just thinks of death, ‘Sho! I am going to die’. And that is where people die. Because if you think of death, you are not going to accept the disease.
– Female, Health care worker, FG5

I discovered in 1996 that I was HIV positive, and with denial that I was – I couldn’t disclose immediately because I had to fight with the feeling and the knowledge, because at that time, ehm, HIV/AIDS was a waiting room for death so it was something that was telling you you are just about to die.
– Teacher, KI23

The association of HIV/AIDS with death was one of the reasons why PLHAs were isolated. It was almost as if people believed that death was contagious. The non-PLHA focus groups and key informants indicated that community members did not want to associate with people who were HIV positive, even if they were healthy, because of the fear of death (FG8, FG9, FG11, FG12, KI6, KI7).

People living with HIV or AIDS were very cognisant of the difference between HIV and AIDS. They did not associate HIV with imminent death. PLHAs indicated that they believed this ignorance was due to the way that HIV education was first disseminated at community
level, with little differentiation between HIV and AIDS, or education on the progression of HIV to AIDS. It was also due to a dearth of positive role-models who had been living openly with HIV for a long period of time (FG1, FG3, FG4).

PLHAs recounted stories of community members approaching them and indicating that they should be dead, or would be dead in a matter of days, thus illustrating their ignorance about HIV and AIDS. Community members were accustomed to people disclosing their status only when they were very sick – “on their deathbeds” – and this had strengthened the association between HIV and death for them (FG1, FG8, FG9).

An interesting trend was noted in the focus groups with young people (FG11, FG12, FG13). It was precisely because they believed they were going to die that young people did not see a need to protect themselves, in other words, many young people said their friends engaged in risky sexual behaviour because they had an attitude of living life to the fullest now, rather than planning for the future.

Young people said their friends believed that even if AIDS did not kill them, they would die of something someday – usually, this “someday” was seen as sooner rather than later; thus the need to live life to the fullest now – which often involved sex without a condom. The future for the young – by the young – was seen to be “next week” rather than “40 years to come”. Youth thus felt the need to “create enjoyment” as a consequence of a general sense of despondency about the future.

We are all going to die whether you are HIV negative or not. They will cite an example that if you do not die of AIDS, you may die tragically. It can be through a gun shot or by being involved in a car accident and you will die, so there is no way you can hide ...

– Male, Youth group, FG11

When you ask the pregnant person or the partner thereof, the response is that at the end of the day, we are all going to die.

– Male, Youth group, FG11

The health care workers, who indicated that they saw many young pregnant women coming into the clinics, mentioned that young women were engaging in risky sexual behaviour. Health care workers were concerned about this behaviour, and they indicated that when young people were questioned about using condoms, they said that they did not use condoms because they would all die someday (FG7), so there was no point in doing so.

4.2.2.2 Promiscuity

I think the reason why people who are HIV positive are not treated like those who have diabetes is that this disease is sexually transmitted; they treat us as if we have done something wrong, that is why my brother here says they compare us with monsters, you see.

– Female PLHA, FG1

Interviewer: It’s like, how does the community view people who are infected with AIDS?

Female 2: They view her as a bitch.

Interviewer: Bitch?

Female 2: Yes.

Female 3: You have been sleeping around, we have been warning you!

– PLHA, FG3

Female 3: In most cases we blame them when we hear that a person is infected, we will say, ‘He has to be infected because he used to sleep around or he was doing this and that.’

Female 2: The community can judge a person; they can even say you see this one cannot last up to two years without getting infected.
Male 1: Like prostitutes.
Female 2: Besides being a prostitute. Sometimes someone is too active ...
Female 3: She might not be a prostitute but her lifestyle ...
Female 2: Her lifestyle is bad ... She can’t stick to one partner. She changes partners. Sometimes you find that she used to be happily married but because of her selfishness you find that her husband left home and she is busy entertaining other men in that house.
Female 3: Especially those who drink alcohol, men buy them alcohol and have sex with them.
– Female social club, FG8

I’ve realised that most of the time when the victim – as I said they are discriminated against – the behaviour in most of the time was questionable. You might say she or he went all out to contract the disease.
– Social worker, KI21

The association of HIV infection and promiscuity was very strong for both PLHAs and non-PLHAs. Women were judged by their behaviour and the places they frequented (e.g. the shebeens). There were clearly “good girls” and “bad girls”. If one of the “bad girls” became HIV positive, or was suspected of being HIV positive, it was seen as her fault – with her lifestyle, it was only a matter of time – and she was ostracised from the community.

Many PLHAs believed that sexual promiscuity was on the rise, and this was ascribed to too much sexual information being made available to young people, and a breakdown of cultural values, which was perceived as leading to more sexual behaviour (FG1, FG3). This view was shared by the men of the social club and many of the key informants interviewed (FG9, FG10, KI5, KI3, KI4, KI13, KI16, KI17).

At the same time, women mentioned, with some anger, that they thought it was men that acted irresponsibly and brought HIV “home” (FG1, FG3, FG8, FG9). However, these women accepted the idea that men needed or would have more than one partner at one time, and that they were unable to be monogamous. The women were more upset with not being able to negotiate the use of a condom.22

Almost all groups mentioned “transactional sex” – young people, usually women, having sex for money and/or other goods – as a problem that was rife. This was related to issues of poverty, unemployment and ascribed gender roles in the community (FG1, FG3, FG8, FG9, FG10, FG11, FG12, FG14, KI13, KI16, KI17).

Young people mentioned that it was peer pressure that led to promiscuity (FG11, FG12). Their youth group ostracised young people who did not conform. This view was shared by the men in the social clubs and some key informants (FG10, KI4). This was described as follows:

The most dominant thing is peer pressure. You see as a young man we do have friends who require of us that we should share some things – either beliefs or style or common things. So because of these common things, we end up compromising what we believe in. For example, there is a bash in a certain area and your friends will come to you and say, let’s attend the party. When you reach that place you start drinking and you end up being drunk and now you get a loose girl. You are drunk, not making informed decisions, you sleep with this girl without a condom, isn’t it a chance for you to catch AIDS? If you could turn down their offer, they think you are not a good someone to hang out with, so they drop you from the group and you will feel out of place.
– Male, Youth group, FG11

22 For more information, refer to para 4.2.5 above.
Even at this level, gender dynamics played a role, with different behaviour ascribed to girls and boys. Young people were less “judgmental” in blaming girls for the spread of HIV. They mentioned that it was often young men, acting as Casanovas, who engage in high-risk behaviour, and that young women were not able to negotiate condom use with their boyfriends/partners (FG11, FG12, FG13).

4.2.2.3 Witchcraft

This issue of HIV is also associated with witchcraft. If a person is facing terminally ill stage, they will relate it to witchcraft. They will argue that ‘the signs are similar to witchcraft’. That is why most of the time they take a sick person to a traditional healer because they think he was bewitched, they don’t want to consider the fact that it is HIV/AIDS, they just say it is witchcraft because they see symptoms of a person who was bewitched. As a result, they don’t want to be closer to that person because they think those things that are in him will be transmitted to them. Like witchcraft, as we know witchcraft is a spirit, no matter how you teach them about this thing, they will not trust you because of witchcraft. So this is what gives them a problem about HIV.
– Male PLHA, FG1

The PLHA and non-PLHA groups both mentioned the association of AIDS with witchcraft. Key informants and focus groups mentioned this as an issue (FG1, FG9, KI13, KI17). When someone died of AIDS, it was attributed to someone having cast a spell on them. Symptoms such as burning feet and legs were deemed to mean someone having buried something in the ground, putting a curse on the person (KI15). Witchcraft was often referred to as makgame and the symptoms included swelling legs, coughing, bleeding (FG9).

4.2.2.4 Contagion

They treat him different from the one who has TB because TB is curable and there is no cure for HIV/AIDS. That is why they treat them different. They think that if you touch someone who is HIV positive, that means you are going to be infected as well by just touching him.
– Male PLHA, FG1

Sometimes when you are cooking, if maybe one [a family member] comes to visit me at home and finds me cooking, she will tell me that ‘hey my friend, don’t dish for me. I’m full’. You will end up realising that this person knows that I’m HIV positive therefore she doesn’t want my food.
– Female PLHA, FG3

The fear of contagion of HIV/AIDS was based on a lack of understanding on the modes of transmission of the disease. Thus, PLHAs related stories about being treated differently by family members, and about their family members not sharing food, utensils, or even chairs with them for fear of catching HIV/AIDS. One PLHA recounted a story of her father not sharing a mug because he was told by members of his church that HIV was contagious (Female, FG 2). Another story was about being chased out of the house if a person coughed because the family was scared of “catching” the disease (Female FG1, FG9).

A woman from the social club recounted a story of a man who was selling Russian sausages in the community. Eventually the rumour started that he was HIV positive and people were told not to buy from him, as he was cutting himself and pouring blood on the Russians in order to infect as many people as possible. Not only did he have to stop selling, but he allegedly died shortly afterwards owing to stress (Female, FG9). Some people were scared of using the same room that a person was staying in (Female, FG9).

Social club members said that fear about the modes of transmission caused the community to stigmatise, for example, by refusing to allow PLHAs to participate in
preparing food for funerals (FG8, FG9), and refusing to share utensils, dishes or cups (FG9).

4.2.3 Separating “us” from “them”

Many people distances themselves from HIV/AIDS, they ignore it.
– Male PLHA, FG1

They just think that a person who has AIDS must just die and must not be helped. If it was said that HIV-positive people must be killed, they would kill us all. They would stone us to death.
– Female PLHA, FG2

You know the way people look at us, I don’t know, I don’t know whether we are manna from heaven. You know when they see you, they don’t even greet you, and they are scared to say hello, they won’t even shake your hand.
– Female PLHA, FG3

They haven’t accepted us. They treat us as if we are from another planet.
– Male PLHA, FG4

AIDS was associated with gay people and all those things. So it’s still seen as an immoral disease or something, so people don’t want to associate with people who have HIV, you see.
– Candidate attorney, KI20

It was clear that there were various reasons for distancing from or “othering” PLHAs. Many of these reasons have been discussed already. It is important to note that PLHAs felt the distancing acutely. In many cases, in order to avoid the painful process of isolation, they engaged in self-isolation, withdrawing from social clubs and social life, and retreating to either a solitary existence or finding strength with other PLHAs only (FG1, FG3, FG4).

This process of distancing was important because it often made it much easier for people to go further and engage openly in discrimination or human rights violations.

The othering was also important because it created a false sense of security amongst people in the community – that becoming HIV positive could only happen to a certain class of people.

Female social club members (FG8 and FG9) recognised that the process of distancing occurred, but usually blamed it on PLHAs, saying that PLHAs brought it on themselves by not disclosing their status to the community. The lack of disclosure led to the community gossiping about the presumed status of the person. Thus, situations existed whereby community members “pass funny remarks” at (Male PLHA, FG2; Female PLHA FG3); “point” at (Female PLHA, FG4); “ignore” (Female PLHA, FG4) and “insult” (Male PLHA, FG2) PLHAs or those that were presumed to be living with HIV or AIDS.

4.2.4 Gossiping

You know when you go out and are dressed nice in the morning they will gossip, ‘She has AIDS’.
– Female PLHA, FG3

Interviewer: So what do you think makes them not to disclose?
Female 2: It’s how people treat them.
Female 3: I think they are scared of what people will say.
Female 1: And you know we people talk too much.
Interviewer: You talk too much?
Female 1: Yes.
Interviewer: Do you gossip about them?
Group: Yes.
Female 2: The thing is the community lacks confidentiality, if I know your problem I would go and tell it to my friend. This is the main problem. That is why people die in silence.
– Female social club, FG8

We only suspect when the community starts making noise about you …
– Male, Youth group, FG11
Gossip was highlighted repeatedly by PLHAs as a means utilised by the community to express its suspicions about a person’s HIV status. The effect of gossip on PLHAs was usually either to strengthen the person living with HIV/AIDS, ie making him or her a “stronger” person emotionally and spiritually, or causing additional stress which resulted in the person becoming more ill. PLHAs highlighted the fact that even their family members engaged in gossip about others that they suspected to be HIV positive, despite knowing how destructive gossip could be. This occurred even if they had lost a family member to HIV/AIDS and had been the subject of gossip personally (FG3, FG4).

Community members from the social clubs, the police and local government recognised the role that gossip played, but blamed those with HIV for trying to cover up their illness, which led to people speculating about what the person’s problems were (FG8). For example, an interviewee from a social club recounted a story of someone in the community hiding his or her HIV status behind his or her TB status. Upon learning that this person was receiving a grant, people became suspicious and began to gossip about the true nature of the person’s medical problem. This fuelled rumours and had the effect of isolating the person (FG8). The level of understanding of the nature and the impact of gossip was quite clear; the social clubs acknowledged that it was damaging, but that it was rampant and would continue (FB2).

Young people blamed community gossip on a lack of knowledge and the levels of ignorance in the community (FG11, FG12). However, they recognised the devastating impact of gossip on the individuals and families who were the subject of such gossip and that it led to people being less likely to disclose their status (FG11).

4.2.5 Gender relations

Gender dynamics emerged clearly in all the focus groups. People agreed that women were more affected by HIV/AIDS. This was sometimes questioned and people wondered if women accessed health services more easily and more often, while men, due to their socialisation, did not access treatment and testing (FG1, FG3, FG4, FG8, FG9, KI3, KI10, KI11).

Some men asserted that women were more likely to gossip than men, and that was why men were less likely to go for testing and for treatment. This was highlighted by at least one PLHA group and became the source of much discussion and heated debate (FG1, KI17).

Besides engaging in “transactional sex” (see section on promiscuity), people regarded HIV as being spread because of the inability of women to negotiate safer sex with husbands and partners. Women who did try to practise safe sex were treated with suspicion – husbands/partners suspected them of sleeping around (FG1, FG3, FG8, FG9, FG10, FG11, FG12, FG14, KI13, KI16, KI17).

Female PLHAs reacted with anger and blamed men for their HIV infection. They indicated that they felt they were helpless to protect themselves, and that housewives were the most at risk for HIV infection:

Female 2: You know men are crooks, when you tell him that I’ve tested positive, he will tell you that this is your problem alone, he is not part of it and it’s your fault. From there he will never come back to see you, he will be gone forever and he will be having sex with another woman without telling her that my previous partner said this and that, he will just keep quiet.
Female 3: And when you ask him that let’s go and test, he refuses. Like myself, my partner, refuses. He doesn’t know his status.
Female 2: They can’t even use a condom.
– PLHA, FG1

You know I’ve realised that if you stay with a man, I don’t know whether they get tired or this thing irritates them, I don’t understand why. They sleep out, you understand. And he sleeps with the wrong people and then he brings the disease home.
– Female PLHA, FG3
I think that the reason why it is mostly women is that women, especially married women, are obedient to their husbands. I have to listen to everything that he says. Maybe he has three girlfriends apart from me. I’m the fourth one and I’m his wife. When he comes back from his girlfriends he will insist that we don’t use a condom. Maybe I am pregnant and I go to the doctor, when he checks me he will find that I’m HIV positive. So that is why we say most infected groups of people are women.

– Female social club, FG8

Many of the women who were HIV positive were seen to be prostitutes by the men of the social club (FG10):

Male 5: Half of those affected are prostitutes and also another half are ordinary girls within the community.

Male 4: Many a times we are not sure what ladies are prostitutes because in the townships we do not have areas where they can conduct their business successfully. So majority of them pretend to be employed somewhere in town only to find that they are prostitutes. And once they are infected, they come back home and continue to spread the disease.

– Male social club, FG10

The fact is some women like vibes. She might be sexually involved with you overnight and the following day she is in another joint and will be entertaining another man and in that way the filth from the two different guys she slept with in two consecutive nights might also contribute to her infection or contracting of the disease.

– Male social club, FG10

Young men considered themselves to be the “weaker sex” because of their powerlessness in front of naked women. Young women were portrayed as having the power in the relationship because of the men’s inability to say “no” to sex (FG11, FG12).

I mean that men in general, we can do anything in our power to get sex. I can pay for sex and after I leave that woman, so I count men as weaker sexual partners because we are vulnerable. Because once we see a naked woman, we cannot behave ourselves. Immediately we believe it is a right thing to jump into bed with her and carry the disease back home. So we like sex and that is our point of weakness.

– Male, Youth group, F11

When discussing the practice of polygamy, the makhosi interviewed agreed that it could spread HIV/AIDS. He emphasised that it was often the woman who was the cause; this was due to the breakdown of tradition in the area because of the empowerment of women:

Sometimes a woman is not satisfied and the man is already on number five and she might find herself a friend and this can bring a lot of problems. The man will have a problem of not being able to tell them what now to do. And you’ll find that it’s there.

– Traditional leader, KI19

4.3 Possible reasons for stigmatisation

4.3.1 Lack of knowledge

Groups generally ascribed the stigmatisation associated with alleged HIV status to ignorance — ignorance of how the disease was transmitted, how it progressed to AIDS, and the association with negative attributes such as death and promiscuity (see previous section). The lack of knowledge about transmission extended to behaviours such as coughing, shaking hands, sharing food or other utensils, and eating beetroot at funerals. It was repeatedly
raised as an issue by PLHAs in terms of the treatment that they received by their families. It was very hurtful and distressing to most PLHAs.

The ignorance was seen by most people as self-imposed; in other words, the information on HIV/AIDS was available, but people chose to ignore it. Health care workers also believed that information was available, but was ignored by people because people believed that it could not happen to them.

I think it’s lack of knowledge, like the example that we have given that people have distanced themselves from the problem and they were not responsible enough to get the education. Education is all over but people will ignore that education and they don’t care. If people know more about this disease they won’t have a problem, they won’t differentiate between TB and other treatments but what makes it different is that people lack knowledge about this disease. They only know about the prevention but they don’t know all the details.

– Male PLHA, FG1

But people have the information even though they ignore it; the information is all over, in the newspapers, on radios and TVs. There is no one in this world who doesn’t know about AIDS. Everybody has the information what is left behind is that people cannot cope with the challenges of life.

– Male PLHA, FG1

Young people claimed that ignorance was rife in their age group and this was the main reason for the spread of the disease. The denial about their susceptibility to infection led young people to remain ignorant, and to refuse to seek out information or the facts on HIV/AIDS (FG11, FG12). In addition, some young people questioned the existence of the disease. Many supported the belief that it was a ploy by government and/or older persons to deny them the opportunity to explore sex (FG12, FG13).

4.3.2 Fear

Related to the lack of knowledge and/or ignorance was fear – the fear that accompanied having a person living with HIV or AIDS at home. Families were seen to be the worst in terms of stigmatising behaviour and this was related to their fear of what the neighbours and others in the community would say. For example, there was a story of an old woman who came in to the clinic to ask for latex gloves; upon investigation, it became clear that she was caring for her daughter who was dying of an AIDS-related illness. However, the old woman refused to bring her daughter into the clinic, or to have someone come to visit the house, as she was afraid of the news getting out to the neighbours, and how it would reflect on her as a parent (KI3).

Another story was about a woman who was ready to disclose her status and live openly with HIV, but her mother refused to allow her to do so, worried about the reaction of the neighbours (FG2). This was clearly related to the association of HIV/AIDS with negative attributes such as promiscuity.

The fear caused people to hide their HIV-positive family members at home:

Male 2: So in most cases, parents like to hide a person who is sick at home.
Male 1: They hide him, oh the one who is HIV positive, they don’t want the community to see them?
Group: Yes.
Male 1: Why is that?
Female 2: And this bothers me because in most cases they hide that person, whereas they don’t like him either. You find that he is locked in a dark room, he is using his own dishes and they don’t
wash them. I can send a seven-year-old child to give him water to bathe, I don’t check if he washed properly. I send a child to give him food and his dishes are washed separately.

Male 2: You don’t want to have contact with him.
– Social club, FG9

The components of stigma have been uncovered to reveal what we regard to be the foundation stones of AIDS-related discriminatory human rights violations.

4.4 Consequences of stigmatisation: human rights violations

The following human rights issues were identified through the focus groups and key informant interviews:

- privacy and disclosure
- informed consent and HIV testing, and
- access to health care services.

4.4.1 Privacy and disclosure

The issue of privacy and the right not to disclose one’s status without consent was a very important concern for PLHAs. PLHAs indicated the importance of deciding how, when and to whom to disclose one’s status:

There is no person who has a right to disclose the status of another person because it’s only a person who is HIV positive to reveal his status; you don’t have that right because you have to talk about your own status, not of another person.
– Male PLHA, FG1

PLHAs also recounted their own or others’ stories of having status disclosed without consent, and how this impacted on them. In many cases, the person to disclose without consent was a health care worker, either a doctor or nursing sister from the clinics or hospital. PLHAs said that although they had filed complaints with the police for defamation of character, the police had not taken the charges seriously. In addition, any complaints filed at the health institution had not amounted to anything. There was agreement in the groups that to see justice done, one had to have money to hire a lawyer.

Social club members and the youth also mentioned the importance of privacy and disclosure. Most recognised the importance of the right to keep one’s status private. The linkages were made between stigma and disclosure of one’s status:

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.
– Male, Youth group, FG12

However, community members stated that it was precisely because of the lack of disclosure that people were vilified in the community. They held the view that it was necessary for people to disclose in order for the disease to be demystified and treated just as any other disease (FG8, FG9). Some people thought that this could be achieved by counselling everyone on the need for a test (FG15).

Various key informants expressed different views. A representative of the South African National Civics Organisation (SANCO) expressed the view that the right of people not to disclose their status resulted in the spread of the disease. For him, AIDS was not a human rights issue, nor was it meant to be (KI4). He reiterated the need for disclosure to prevent others from making the same mistakes (FB4).

For caregivers employed by or volunteering at AIDS service organisations (ASOs), confidentiality was seen as problematic and as limiting the extent of assistance that they could provide to PLHAs (KI5). They argued that the inability to disclose the status of a person to
colleagues and other caregivers such as family members impeded patients from receiving the best care available.

Health care workers also saw confidentiality as a problem, especially when they were unable to disclose the status of a patient to a family member who would act as caregiver. However, this was related more to the need to protect the family member/caregiver, rather than to ensuring that the patient was given the best possible treatment at home (FG6 and FG7).

The other problem is that of confidentiality ‘cause when you do counselling you tell the client it is between me and you. And then the relatives, well maybe the person who is positive, they don’t know about that. And then because at the end, they hide it from the grannies, because of confidentiality and then you find that the granny does not know how to handle the kid who is positive because she hasn’t been told. You have to tell the granny she must handle the kid that way and she asks why and you end up telling because she has not known why so I have to handle her differently. Then if you then tell, it means that confidentiality is finished.
– Female, Health care worker, FG7

4.4.2 Informed consent and HIV testing

Most people, including health care workers and PLHAs, shared stories of being tested without giving consent, without pre- and post-test counselling, or being told, “You are HIV positive and you will die” (FG1, FG3, FG4).

Respondents agreed that testing was a traumatic experience and it took a great deal of courage to finally have a test. Most women, including nursing sisters, had been tested during pregnancy, often years ago, and had not been retested since (FG6 and FG7).

Observation undertaken at the clinics illustrated that there was little by way of confidentiality and the right to privacy when going for an HIV test. Most clinics did what they could with the limited resources that they had; often the counselling took place in a room that doubled as a medicines store-room, or storage space, with people coming in and out.

Female 3: It’s not easy to go for testing at some places. Because why, there are no ... there is no privacy because the office of counselling, you have to go for counselling and everybody knows that that office is for counselling and you have to walk in front of other people to that office. They counsel you and after counselling you, you have to go for testing and you have to go again in front of those people knowing, those people know that there you went for counselling, you go for testing. After getting the results if people are there they can see ...

Female 1: Your face shows that something is wrong.
Female 3: Yes, it’s wrong. You are positive or negative. They will know exactly the results.
– Local government councillors, FG15

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:

OK, in the clinic where I work ... there is a counsellor who does the counselling. So no person can have the test without being counselled. All will go for proper counselling. This is one of the biggest problems and if you think you’ve got to see in the morning, we are talking about nurses in the antenatal clinic and out of 20 or 30 women, if you spend, a proper counselling will take 20 minutes at least. We haven’t got the time to do it. It’s unrealistic to think that they can. Add that on to an already extremely busy worker ... All the sick patients arrived that day, they are going to do all the administration, including checking the medicine, order medicine and all the administration,
nurses off duty ... Anyone who wants to add to that during the 20 minutes of counselling on 30 patients per day, it’s unrealistic, totally unrealistic. Even with a dedicated counsellor, he can’t do it. There is not enough time to do it, to do it properly. – Clinic doctor, KI15

HIV testing was seen to be on the increase because of the access to disability grants, and both health care workers and members of the social clubs regarded this with some cynicism. Health care workers claimed that young people, especially young girls, were falling pregnant simply to access the child support grant, even though the information about the risks of STDs and HIV/AIDS was available to them (FG5, FG6 and FG7). This belief was reiterated in the feedback sessions held and was the subject of heated debate (FB1 and FB4).

Female 3: ... So people just want to come for grants. They don’t want to know their status, they just want to come there and have the grants. They just want to have the money, the grants.

Male 1: And the other problem is, that encourages this is, the one of unprotected sex is the very grant that they are going to have. It leads to one to have sex because grants are available.

– Health care workers, FG5

The community groups expressed worry about welfare abuse by people claiming to be living with HIV/AIDS. There was a perception that unscrupulous doctors were signing the requisite forms for healthy individuals, making them eligible for grants (FG8, FG9, FG10). When challenged on how to deal with this issue, community members indicated that there was a need to retest all PLHAs in the area, even if this involved being locked in a stadium and being forced to retest, as this was the only way to curb welfare fraud (FG8). This issue was seen as overriding the need for informed consent for HIV testing (FG8).

Access to disability grants was a vital issue that was raised in all PLHA focus groups. The issue of forced HIV testing was seen as quite problematic in general. While not raised by all groups, in one focus group with health care workers it was suggested that all pregnant women be forced to test for HIV (FG6). A discussion ensued about the need for testing of both partners, rather than victimising the woman only. Other groups recommended that only counselling be mandatory, and that the decision to test be left to the persons involved. This was seen to be an effective way to destigmatise HIV/AIDS (FG15):

That is why I am saying maybe if counselling was compulsory, not testing because testing is a secret of a person. If counselling was compulsory so that even in the meeting we counsel each other, people will know that this disease is a disease like any other disease. You can have cancer, you are diabetic, you have high blood. It is still a sickness. So maybe it will be better.

– Female local government councillor, FG15

Finally, there was a broader discussion about informed consent, and what that constituted, and whether it was in fact possible to get informed consent from someone who was sick and in pain:

And what about consent? Is it really informed consent? I don’t think so, I don’t think so because basically they are sick, they are in pain, they want to get better. And then they stay with you for five minutes and nine times out of ten you are sure that this consent form, they are going to sign it. Even you the person who does the counselling, you know it. The other thing is whether this pre-test counselling, is it done the way it should be? Do you think so? If the people need their rights, do you think, I don’t know.

– Social worker, KI21
However, nurses said that they acted as the patient’s advocate if he/she was being pressurised by the doctor to go for testing but did not want to do so. Nurses were confident that no forced testing was being undertaken at their hospital, although at other hospitals testing without informed consent was a matter of course (FG6).

### 4.4.3 Access to health care services

Both PLHAs and members of the social clubs complained about the treatment that they had received at the hospital and clinics in the area.

People from the social clubs complained mainly about the waiting period, that there were no doctors available and that the drugs were never in the pharmacy. They were generally dissatisfied with the treatment that they received when visiting the hospital. They alleged that it was useless to complain since the suggestion boxes that were at the hospital were opened and the suggestions reviewed by the clinics supervisors themselves, who simply removed all complaints (FG8, KI3). As one woman said about being ill and having to go to hospital:

> I won’t go there, I will stay away.
> – Female social club, FG8

The youth had not heard stories about the hospital. Presumably, they did not use the services of the hospital and had not seen or heard of ill treatment by health care workers (FG11, FG12, FG13).

Most people from the community had heard of specific wards where HIV-positive patients were segregated (Ward 2, Female PLHA, FG3; Ward 2, FG9; Step-down ward, FG8, FG9), or specific diagnosis codes that were used to identify those with HIV (Diagnosis code “279”, FG9). However, the alleged segregation was denied by the health care workers who argued that, no matter which ward HIV-positive persons are in, it was seen by the community as a ward for HIV-positive persons simply due to ignorance (FG6, FG7).

The right of access to health care was a major issue for the PLHA groups. Each group raised the issue of treatment by health care workers. They saw their ill treatment 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 that they received at home, to the treatment that they received at the hands of the health care workers. Many PLHAs recounted stories of ill treatment of themselves or other PLHAs by nurses. Most were able to recount stories of being forced to wait to go to the bathroom, being told to “go yourself”, staff disclosing status and gossiping about patients in front of others, staff passing “funny remarks”, staff refusing treatment, staff giving the wrong medication, and placing of HIV patients in specific wards (FG1, FG2, FG3, FG4).

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 pains and needs an urgent help, therefore they must give him the special attention; they just become harsh on him. I don’t know why they do that. Sometimes they send that sick person back home, so if a nursing sister tells you to go back home it becomes tough.

> I don’t want to go to the hospital, we don’t want to go to the hospital, we stay here at home.
> – Female, PLHA, FG3

Nurses, on the other hand, complained about the pressures that they were under, including unrealistic expectations...
from patients. They vehemently denied treating PLHAs differently and that people with HIV were segregated in specific wards. 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 affected psychologically by the numbers of people who were dying in the hospital and that they saw on a day-to-day basis. They also complained about visitors coming to “snoop around” instead of to visit patients (FG6, FG7).

Nurses blamed families for treating people with HIV badly. They cited examples of family members dumping patients in the hospital, not coming to collect discharged patients, and patients being admitted when they were dirty, showing that they were not cared for at home. Nursing sisters said that the patients appreciated all that they did for them (FG6, FG7).

The problem is patients are being discharged and after that they stay for a very long time without being fetched from the hospital. The relatives don’t come. Or maybe they come, it’s a problem for them to decide who is going to take the old granny home and it becomes a problem now. And another thing, I think that if, at home, if it is that granny is sick at home, they take a long time before they can bring the lady to the hospital, neh. And then after that you find that when they come and visit, they will complain, no, she is not being handled properly, she’s not being cared for properly, whereas the problem started at home. That is what we are facing ...
– Female health care worker, FG7

Even at home, they are being treated bad, are being ill-treated. When they come to the hospital, they are filthy and some of them have bedsores to show that they are not being taken care of. As filthy as the patient is, they leave the patient there and then expect the nurses to take good care of the patients, and they didn’t take care of them at home. You tell the patient and we will try our best and at the end they do not get satisfied. At the end of the day, they will complain that their brother or sister is being ill-treated. But at home they leave the patient alone and go away.
– Female health care worker, FG7

People expect a lot from us as nurses. If you try to explain to them, they don’t understand and say that you are not helping us.
– Female health care worker, FG7

And most of the thing I think it is just the stigma. We are just like AIDS people, we are being stigmatised, that nurses are bad. It’s just labelling.
– Female health care worker, FG7

So we like our jobs even though the community labels and stigmatises 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 ...
– Female health care worker, FG7

During the feedback session with social clubs (FB2) and PLHAs (FB3), people again reiterated the discrimination that they felt they faced at the hands of health care workers. People did not agree with the argument made by nurses, and instead indicated that nurses “had an attitude” about people with HIV/AIDS. There were new stories shared about the ill treatment of people with HIV/AIDS at the local hospital (FB3).

4.5 Other human rights issues

4.5.1 Access to social security

The high levels of poverty and unemployment were identified repeatedly in focus groups and in key informant interviews as major problems in the area (FG8, FG9, FG10, FG14, FG15, KI4, KI6, KI12, KI14, KI16, KI17). The high level of unemployment was seen to be the cause of many social problems, such as drug and alcohol abuse, crime, domestic violence, rape, prostitution, and learners
withdrawing from school and/or being unable to continue with their studies past Grade 12, due to an inability to pay fees (FG14, FG15). Thus, social grants were seen to be vital for survival, and many people said that they were receiving one form of grant or another.27

Disability grants were identified in all of the PLHA groups as being extremely important for survival. PLHAs complained about the time that it took, approximately three to five months, between applying for and finally receiving disability grants (FG1, FG2, FG3, FG4). The importance of the disability grant for people living with HIV or AIDS was reiterated at the feedback session with PLHAs (FB3).

You know after receiving my money you know I will stay at in my house and eat whatever I like. You know I will go nowhere ... I just want the government to give me money and die with a full stomach.
– Female PLHA, FG3

I hope God helps me with my social grant. I have no one on my side.
– Female PLHA, FG3

You see, psychologically you already raise your hopes that in the new South Africa, your standard of living will be high. But if you’ve got no means of income, how will you ... so anything that comes your way, you are going to grab it. And I’m not blaming them.
– Social worker, KI21

The reason why I went to test is that I needed money. I heard that people who are HIV positive receive social grants. So I went to test and they said I’m HIV negative. I was so disappointed because I knew that after this month I would get R4 000 ... My intention was to get money because I don’t have money and I’ve got kids you see, so I went there and they tested me and said, you are negative, so I told that counsellor that I was supposed to be positive because I need money. I know that when I wait for six months I’m going to get close to R4 700 for the first month and the next month I’m going to get R740 every month.
– Female, Social club, FG8

There was some confusion associated with the eligibility for disability grants – whether people were eligible immediately after testing positive even if they were healthy, or if they were only able to access the grants when they fell ill, and their CD4 was below a certain level. The nursing sisters acknowledged that the grants were to be provided to people with CD4 counts of less than 200, but thought that it was useless to give people grants when they were dying (FG6). A clinic doctor suggested that grants were meant to be primarily for people to obtain good nutrition to prevent them from getting very ill, so he completed the disability forms, whatever the CD4 count of the patient (KI15).

Interviews with the Department of Social Welfare (KI12) indicated that in the Hammanskraal and Temba area, it

27 Such as the foster care grant, child support grant, or disability grant. See Appendix 2 of the original report for statistics on sources of monthly income of interviewees.
was possible for a person to access a grant as soon as he/she tested positive, and that this was one of the reasons that people were coming forward to test. The issue of CD4 count had not been standardised in the area yet, although the Department was investigating the matter and some standardisation would probably occur in the near future.

The state was seen as violating people’s rights by making grants difficult to access. The example of foster care grants was given as an example in various groups.

The significant role of social grants indicated that realisation of the rights to health and dignity was bound up with other sets of rights, such as the right to social security, and that these other rights themselves impacted upon right to health (both positively and negatively).

4.5.2 The rights of orphans and vulnerable children

Most groups and key informants raised the issue of young orphaned children as a significant concern for the area (FG9, KI2, KI5, KI12, KI13, KI14, KI17). The ASOs focusing on home-based care identified the difficulties that faced children: being called names at school (KI5, KI9, and KI10), being responsible for younger siblings in child-headed households (FG9, KI9), and having limited access to grants, often due to lack of documentation (K112 and KI22).

The difficulty in accessing foster care grants for children, usually left in the care of grannies, was highlighted and this was seen as due primarily to a lack of documentation. Thus, children were being cared for by grannies on small pensions that were insufficient (KI2). While the local Department of Home Affairs said that it was working hand-in-hand with social workers to offer assistance to people to access basic documentation, including using mobile units (KI22), the activities undertaken by social workers and the Department of Social Welfare were seen by the community as inadequate (FG14, FG14). The lack of resources was linked to children engaging in crime, having sex for money and goods, and being more susceptible to rape (FG14, FG15).

The social worker who was interviewed expressed her frustration at the lengthy process required by legislation before the issuing of a grant, and indicated that social workers were working on applications received two years previously (KI21). She thought that the community did not understand the serious pressures that social workers were under.

4.6 The role of stakeholders in the community

4.6.1 Family

The family is not supporting you ... Like if you drink tea with a cup, anything that you use they don’t want to use it ... and then even if you sit on the chair, no one wants to sit on that chair again, you will be using it alone ... and sometimes when you cough they chase you out of the house, they don’t want you, they say you will infect them.

– Male PLHA, FG1

Gradually we are forced to accept. But on the other hand, I think some family members, they think it is proper to punish the victim, especially if the victim’s manners before the disease was not desirable. So they think it is proper.

– Social worker, KI21

It starts in the family, and when the community hears about it, it gets worse.

– Female PLHA, FG3

Most PLHAs did not count on family for support. They said that family members treated them badly, and many had not disclosed to members of their families. Most
were able to share stories about friends and acquaintances who had been kicked out of their homes after disclosing their status and told to stay in the outhouse or the house in the back, had not given proper food to eat, had suffered abuse at the hands of their family members, and had been isolated and hidden from the community owing to a fear of what the community would say (FG1, FG2, FG3, FG4). This was often ascribed to a lack of knowledge about HIV/AIDS, and also the association of HIV with negative attributes such as promiscuity. 

One woman in FG1 recounted a story about her in-laws coming forward, after hearing that she was sick, to claim all of the goods in the house. They were shocked to see her still healthy and strong. Both the candidate attorney (KI20) and the head of the legal aid clinic (KI1) confirmed that there were many issues in the area related to estate matters, reflected in families fighting for the house and other goods after the husband had passed away (KI13). This was related to blaming of the wife for allegedly bringing the disease into the home.

Most community members also told stories about people being isolated from the community by families for fear of what people would say (see para 4.5). They attributed this to a lack of information and the ignorance of older people in the community. The need for family counselling was also repeatedly identified, to enable all family members to come to terms with the disease (FG6, FG7, KI9).

Health care workers claimed that while families often blamed them for the ill treatment of family members, it was the families that ill-treated those with HIV/AIDS most. This manifested itself in “dumping” people in the care of nursing staff and not collecting patients who had been discharged.28 Health care workers also expressed their frustrations about not being able to disclose the status of a patient to a caregiver, so that the caregiver would be in a position to protect himself/herself. They believed that often HIV-positive people were ill treated at home because the family members were not aware of how to treat someone who was HIV positive. 

Young people attributed the lack of support from the family to the issues of ignorance and gossip. Families were worried that the HIV status of their family members reflected badly on them, that they had failed to raise children with proper social and moral values, and that this impacted on the treatment of the family in the community (FG11, FG12, FG13).

4.6.2 Faith-based organisations

Most PLHAs said that they had renewed their faith in God, and that they felt quite spiritual. This did not necessarily mean that they attended church, however. PLHAs repeatedly indicated that they prayed, that God made them feel strong, and that it was God who would take away their lives, not AIDS (FG1, FG2, FG3, FG4).

I also have reference of God, It is written in the Bible that ‘life comes from God’, therefore HIV doesn’t own a person’s life, it might be there but it cannot decide when your life will end, your death will come but it won’t be decided by HIV. God will decide and I will accept.  
– Female PLHA, FG1

But in 2001 when I decided to disclose because that was when I had realised that, fortunately, by believing in God, you know, I had my faith in God and my life is in God’s hands. So he is the one that will determine when I am going to die, for how long I am going to live.  
– Teacher, KI23

While having faith was seen as a support for most PLHAs, the social clubs identified churches as problematic (FG8, FG9, FG10). Certain faith-based organisations were seen

28 See also para 4.4.3 above.
to be misleading PLHAs, and were regarded with derision. The practice of prayer and the use of holy water and holy coffee was deemed to exacerbate the spread of HIV/AIDS in the community.

There is a religion that discourages people from going to the doctors when they are sick, like –. I’m sorry to mention the name of the church ... Like –, they believe that you have to use their holy water and pray. If you go to the doctor that means you are going against the rules of the church. So those who go to the doctor do it in secret because it is said that you have to confess your sins. I go and consult the traditional healer, I have to come back and confess to the preacher that I went to the traditional healer.

– Female social club, FG8

Now guys who go to – say they don’t use condoms because the church told them that they can’t be infected. They say they drink holy coffee.

– Male social club, FG10

In key informant interviews with two church leaders, it emerged that the church had not played enough of a pro-active role in the HIV/AIDS pandemic (KI6, KI16). The church had primarily provided emotional support through prayer to parishioners. It was obvious that HIV-positive individuals were not comfortable to disclose to their congregations, with only one of 250 having disclosing publicly to the congregation, and only three more disclosing in private to their pastor (KI6).

4.6.3 Health care workers

Most PLHAs in focus groups expressed serious concerns about the treatment that they received at the hands of health care workers, especially those from the local public hospital. Many expressed the view that, even if they were in the terminal stage of AIDS, they would not want to be taken to the hospital, because of the poor treatment that HIV-positive people allegedly received there. Community members shared this view of hospital care (see section 4.4.3 above).

However, the clinic doctor who was interviewed defended health care workers by describing a typical day at a clinic as follows:

...The average nurse is alone in the clinic. Anything can happen at the clinic at any time. She feels under-appreciated, under-supported, drugs happen to run out because the van is broken and she is sitting without medicine and any moment now she can have an emergency landing on her door. And then she will have an administrative task to do. And she will have someone going off sick, and then she will have to reorganise the thing and then she will miss the bus and so on. It is extremely stressful to them, and there is little support that is backing up nurses and health care workers.

– Clinic doctor, KI15

In feedback sessions with PLHAs and with the social clubs (FB2 and FB3), ill-treatment by nurses at the local hospital was reiterated.

4.6.4 The police

They don’t know their status but when you go there to complain, they don’t take you serious. The police don’t understand us. They just say whatever they like. What we want is respect, you see, because we are also human beings. If we go to the police station, maybe you are going to report that your wife had hit you, they laugh. If you complain that a person is spoiling my name by saying that I have AIDS, they laugh and say, ‘What must we do?’

– Male PLHA, FG1

See also para 4.4.3 above.
PLHAs regarded the police as being insensitive to their needs, and providing them with little assistance. When they were approached, usually in cases of unauthorised disclosure of HIV status, the police were seen to be unhelpful (FG1).

Female 1: What happens if you go to the police? Does it help to go to the police?
Female 2: I don’t think it helps.
Male 1: It’s a long procedure, they will tell you about so many things and you end up giving up.
Female 2: They will just waste your time.
Male 2: Yes, you end up losing interest because there are no right channels to take if you are in situations like that. The police will tell you about so many things as you know how the law works; they will argue that they have to do some investigations and your case will end up disappearing without being processed. Unless you have money, in that way you can hire a lawyer to take care of your case, without him it’s very difficult to process things on your own.
– PLHA, FG1

The police, however, claimed that they treated all cases that were brought to them as of equal importance. This included cases of defamation due to unauthorised disclosure of HIV status. But they said that the community did not understand what the requirements were for a successful case of defamation of character, and most often the criteria were not fulfilled. In any event, the police said, it was a civil matter and there was little the police could do (FG14).

4.6.5 National Association of People Living with HIV/AIDS (NAPWA) and the Treatment Action Campaign (TAC)

Female 1: There is another one called AIDS what, what. What is it called? I used to hear about it on TV. They say if you have domestic problems you must come and see them.

Interviewer: Where is it located, is it around Temba?
Female 1: I heard about it on TV.
Female 2: We don’t know where to complain here in Temba.
Female 6: They don’t discuss anything with us, they just come here and drink cold drink and go home (Giggles).
– PLHA, FG3

One of the focus groups of PLHAs mentioned that large AIDS organisations such as NAPWA and the TAC should be able to provide assistance with problems, but said that they did not play a role in Hammanskraal (FG3). The large organisations were perceived with some suspicion, and were seen to be visible only when they needed support for some campaign. Many PLHAs had paid R5 for membership to NAPWA, but were not clear about the services it offered or even whether or not there was a branch in Hammanskraal or Temba (FG3).

Young people agreed that there was a need for organisations such as NAPWA and the TAC to advertise what they did and the location of their offices, in order to make them more accessible to the community (FG11). One key informant indicated that TAC was problematic because it did not engage in sustained programmes, but only came to Hammanskraal during campaigns (KI5).

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. During the research period, there was a planned re-launch of NAPWA. While several people waited at a meeting venue for several hours, NAPWA representatives did not turn up. Thus, it appears that TAC and NAPWA played little, if any, role in the area.

4.6.6 Traditional leaders

Female 4: Hammanskraal is far from important things, you understand. What exists in Hammans-
kraal is the tribal council. When you say someone insulted me they will say, go and slap her.

Female 2: What happened to R5 we used to donate? [Donation for NAPWA branch]
Female 3: And if you hit someone who insulted you, you get arrested.
– PLHA, FG3

That’s the practice around here. They have to go to the kraal first. But they usually don’t get help there because they – it seems as if they give first preference to the families.
– Candidate attorney, KI20

Traditional authorities still played an important role in the area. Key informant interviews highlighted that people still went to the traditional authorities to settle disputes, often before approaching other organisations (KI5, KI20). Women from the community usually went first to the traditional leader when their partners died, in order to deal with issues that arose within their families. However, the traditional leader was seen as giving preference to families over the rights of the women (KI1, KI20).

The traditional authority was not supportive of women’s rights, and this was highlighted in the key informant interview with the makhosi who indicated that the Constitution and Bill of Rights were bad because they distorted the traditional balance of power in favour of women, which allowed women to “refuse to cook” or refuse to have sex on demand. He considered this to be disruptive of the traditional culture of the villages (KI19).

The makhosi who was interviewed said that he tried to raise the issue of HIV/AIDS with other leaders in the area, but that they were not receptive to the issue. He was considered to be too young to be discussing such issues – those related to sex – with the elders. Most AIDS service organisations confirmed the view that traditional authorities were generally not supportive of HIV education and awareness programmes (KI6). However, a traditional leader did sit on the Local AIDS Council (KI2).

Local government councillors also complained that many traditional leaders were not helpful in the development of the area:

So talking about traditional leaders, it is not easy for the makhosi to get in line with the reconstruction or with the municipalities because they know ... they think the councillors are coming to take their leadership. But we are still working with them, we are still working to make them understand the ... maybe the Constitution, that the municipalities are there not for the purposes that they think they are there for ...
– Female, Local government councillor, FG15

However, the local government had encouraged the involvement of traditional leadership at the ward level and this had proved relatively successful. Four traditional leaders were also local government councillors.

4.6.7 Local government

Most members of the social clubs saw the local government and ward councillors as being of little consequence or having little impact on the lives of the community (FG8, FG9, FG10). People often complained that the councillors were only present during elections, but did not deliver on promises made. They identified problems with roads, water, and other basic services.

Female 2: To tell the truth, our councillor plays far from community issues. He is just concentrating with his supporters. Am I lying?
Female 1: No.
Female 2: He is concentrating on his family and girls who can go with him to certain rallies but

See also comments on polygamy in para 4.2.5.
you won’t see any progress in Marokolong ...
– Female, Social club, FG8

Local government councillors also identified the issue of slow development as a major concern, but cited as causes the presence of traditional leaders, the fact that the area was relatively new (having been demarcated only in December 2000), and the fact that backlogs existed. Councillors said that they had a good relationship with the cross-border municipality, and that there was sharing on certain projects. However, there was no budget sharing at present (FG15).

In terms of their role in dealing with HIV/AIDS issues, it appeared that local government councillors felt that they needed to undergo counselling training, so that they were able to counsel their constituents about issues related to death and dying. While an AIDS programme had been included in the Integrated Development Programme for the Municipality, it had not yet been implemented (FG15).

The communication between local government and the provincial sphere of government was highlighted as problematic. Local government councillors expressed their frustrations about the issues of foster care and disability grants, and the need for social workers to deal with backlogs in a timeous manner. They indicated that consultation thus far with social workers had proved to be fruitless (FG15).

The Local AIDS Council (LAC) was created by the Moretele Municipality to coordinate all HIV/AIDS programmes and organisations within the municipality. According to the chair of the LAC, it comprised representatives of NGOs, traditional leaders, provincial government line departments, the youth sector, local business people, and PLHAs, amongst others (KI2).

Most key informants, especially those involved in the ASOs, complained that the LAC was ineffective; it did not fulfil its mandate and had to learn to “differentiate between politics and the disease”. The LAC was accused of making HIV a political issue, and ignoring the real issue of people who were suffering and dying at community level (KI5, KI9, KI10, KI12, KI17).

4.6.8 Traditional healers

The importance of traditional healers to the community was reiterated by key informants (KI9, KI13, KI15).

Interviews revealed that when a person was ill, it was often perceived as due to witchcraft, and traditional healers were then approached for treatment. In the feedback sessions, the attribution of witchcraft was ascribed to the lack of disclosure by the person living with HIV or AIDS: if he/she did not disclose his/her status, the family did not know what was wrong and then tried to get help through the traditional healer, especially since the symptoms looked like they were related to witchcraft (FB4).

In Hammanskraal and Temba, traditional healers had been involved in trainings on issues related to HIV/AIDS through the University of Pretoria, the Department of Health or the municipality. There were representatives of traditional healers on the Local AIDS Council. The traditional healers had also engaged with AIDS service organisations and they worked together to assist those living with HIV/AIDS (KI2, KI9).

Perhaps due to the training and engagement with community based organisations, or due to the fact that traditional healers believed that AIDS was curable, there was little stigma associated with HIV/AIDS. The traditional healer interviewed told us that she had successfully cured at least four people living with HIV/AIDS, but was not able to disclose their details due to patient-health care worker confidentiality (KI7).

4.6.9 Other stakeholders

Other stakeholders mentioned during the research study as possible places to take human rights complaints included:
• the Department of Labour as a possible place to take labour-related matters. No groups were clear as to how or who to contact in the case of human rights violations.
• the South African Human Rights Commission, but there was no indication of knowledge as to how the Commission could be contacted or what areas it covered.
• the Public Protector was mentioned, but there was no indication of knowledge of how to contact him and what areas he covered.
• an organisation known as Women Against Women Abuse (WAWA) was mentioned as providing services for women suffering from domestic violence. However, it was far away, in Stinkwater, and not accessible to many people in the community.
• a human rights organisation known as Masana was supposed to exist in Hammanskraal. However, several attempts to contact Masana proved unsuccessful and their offices were locked up when visited.
• the satellite Legal Aid Clinic of the University of Pretoria was identified as a potential place to take human rights violations. However, interviews with the director and a candidate attorney indicated that the clinic covered mainly criminal work, and did not handle cases related to HIV/AIDS and human rights.

Most people do not know about their rights. There is a lack of knowledge as they had not read or been exposed to the Bill of Rights.
• There are many difficulties in making rights real. It was questionable whether this was possible in an environment of poverty and unemployment.
• The community is not aware of how to enforce the rights that have been violated. Many people were not able to mention one active human rights organisation/institution in Hammanskraal where they could go to seek assistance with their problems.
• Many people saw human rights as a problem, rather than as a means of empowerment.

These issues will be discussed briefly in turn.

5.2 Lack of information

No okay, the Constitution protect us, but the people don’t partake.
– Male PLHA, FG4

Yes, I’ve started seeing it since 1994 after we voted. But we don’t usually read it.
– Female social club, FG8

We know what it is [the Constitution], but we are too lazy to read.
– Female social club, FG8

When asked about the Constitution and the Bill of Rights, the majority of people interviewed were able only to recognise them, but not give any details on what was in them. Questions on the Bill of Rights were met with silence or vague answers about rights, not what those rights entailed in a practical sense. Thus, there had been little in terms of dissemination of the content at community level. This impacted on people’s ability to claim their rights – if a person did not know what they were, they would not be in a position to recognise human rights violations and claim enforcement of rights.

5. Is a Human Rights Approach at Community Level Sufficient?

5.1 Introduction

In Hammanskraal and Temba, it was clear that the human rights approach to HIV/AIDS was not effective at community level. The ideals that are espoused in international and national guidelines and policies, and the rights contained in the Bill of Rights and other protective legislation had simply not permeated down to community level. This could arguably be attributed to a number of factors, including:
Other laws that deal with non-discrimination such as the Employment Equity Act\(^\text{31}\) were also not known to the community.

### 5.3 Making rights real

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.

– Male, Youth group, FG11

Related closely to a lack of knowledge of human rights, many people indicated that it was not possible for them to exercise their rights. They felt helpless and disempowered in trying to achieve access to basic rights such as health care services and social assistance. They felt that complaints made, for example, to the Department of Health fell on deaf ears and nothing was ever done to change the situation. Similarly, members of social clubs complained about the lack of development in relation to water, electricity and other basic services; they did not feel that local government was able to deliver these services, and more importantly, they felt that they had no recourse anywhere to complain or to make a difference.

The key informant interview with the social worker highlighted the fact that people in the community could not make rights real because they prioritised other issues, such as poverty, and human rights were seen as secondary, or almost a “luxury” item (KI21). The linkage between the alleviation of poverty and the protection and promotion of human rights was not made.

The teacher who complained about being discriminated against after disclosing her status at school, indicated that she did not have any time to deal with the violations because she was busy working (KI23). The social worker highlighted a similar issue, which was that the focus on work and the pressures that she faced meant that issues such as human rights took a less significant role in her life. She surmised that the same was true for the rest of the community (KI21).

Another reason given for the failure to access human rights was the link between stigma and discrimination. The link was recognised in many groups, and stigma was seen as one of the primary reasons why people did not speak out and try to enforce their rights in the community (FG1, FG3, FG4).

### 5.4 Few organisations to assist with enforcement

Even when violations occurred and were recognised, 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 assist with problems. Many people interviewed could not name any organisations in the area that could be of assistance. People mentioned having to go from one place to another to try to obtain help with problems. For example, in trying to deal with family violence, women were usually sent to the police and the courts, and did not have sufficient funds for transport to do this. Other people mentioned that they do not know where to go to report abuses such as unauthorised disclosure by health care workers and doctors (FG2, FG3).

Organisations such as the Department of Labour or 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 what areas organisations covered. While the municipality indicated that it was possible for people to come to it for assistance (KI2), most people felt that the municipality had little to offer.

---

\(^{31}\) Act 55 of 1998.
It was actually difficult to find any organisations in the community that dealt specifically with human rights violations. Those that supposedly did, such as Masana, were not accessible even to the researchers during the course of the study.

5.5 Human rights: Solution or problem?

The police saw the Bill of Rights as preventing them from doing their jobs properly, and argued that education provided to the community about the 1994 Constitution did not include educating people about the accompanying responsibilities (FG14). The traditional leader interviewed claimed that the Bill of Rights was eroding the traditional way of life in the villages, and causing the breakdown of traditional values (FG19). PLHAs alleged that access to information for young people made them more likely to engage in sexual behaviour, thus leading to a faster spread of HIV.

Nurses alleged that access to child-care grants made young women fall pregnant to gain access to money (FG6, FG7). Local government councillors argued that the rights in the Constitution accorded to traditional leaders were a problem for development of the area (FG15). Male social clubs (FG10) alleged that there was a misuse of the freedom of speech, that children had too many rights compared to their parents, and that was why they were able to engage in sex and their parents were unable to comment on their behaviour.

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 as they are raised at the community level, since they display a disjuncture between thinking at global and local levels.

6. Conclusion

6.1 Introduction

The primary purpose of the Tswelopele study was to examine the impact of a human rights approach on one localised community setting in South Africa. The study used stigma as a point of entry to examine broader issues of discrimination and human rights violations, and whether a rights-based approach to HIV/AIDS had reached community level.

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. The findings on labelling, blame, gossip and social exclusion of PLHAs, or those suspected to be HIV positive, show an apparent disjuncture between rights and reality. Whilst 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 communities from which they come may be quite different.

Perceptions about risk, routes of infection, physical characteristics, behaviour and the power of the supernatural all contributed to a powerful social response. This may not be a well co-ordinated or conscious response but each component and aspect combined to create a social milieu in which stigma and prejudice were able to flourish despite the recognition or understanding of rights.

People are still subject to human rights violations and have difficulties in making their rights real. It is clear that just informing people about their rights and the rights of others in itself may not be sufficient to challenge the deeply embedded social constructions of the other and justification of mistreatment. Importantly, often people believe that human rights are a burden, or a luxury and only relevant to those who can enforce them. Much must still 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 the perceptions are formed and placing the challenge there. This could include targeting persons and institutions which 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 – finding ways in which a different social construction can be developed to make people trust the law and appreciate rights can work for the wider social good.

It is envisaged this project will address some of these aims through a community-wide training process to educate about HIV and AIDS, about stigma and about rights. Some other recommendations to enable this to happen will be discussed below.

6.2 Recommendations

We make the following recommendations. It is clear that implementing the recommendations will require a concerted effort by all stakeholders, rather than focusing on one area or providing once-off training events.

- While education and awareness-raising programmes have been in place for several years now, it is still important to review, update and continue such programmes. These programmes should, in addition to addressing the groups who are currently the focus, aim to educate older persons – the “grannies” – who are usually left with the burden of caring for sick children. These programmes should include basic principles of human rights, how to recognise human rights violations, and where to go for assistance.

- Basic HIV/AIDS education is required for the police, traditional leaders, the municipality, and faith-based organisations in order to destigmatise issues of transmission. Human rights components should be incorporated in this training and, in addition to covering issues such as violations and where to go for assistance, they should address the real concerns that these groups have about human rights being problematic.

- Training for municipal officials should focus on helping them understand the role and responsibilities that they have as municipal officials and councillors to respect, protect and promote human rights. The municipality could consider establishing a “human rights desk” in order to coordinate the human rights activities undertaken at municipal level.

- Capacity building of the Local AIDS Council (LAC) is necessary to ensure that it functions effectively. The LAC should also be assisted to engage in public relations so that people can understand its mandate.

- Basic HIV/AIDS education is required for family members. They can be accessed through social clubs, at clinic waiting rooms, and through drama. Education should also include training on human rights violations.

- A “refresher” course on HIV/AIDS is required for health care workers. This requires training on ethical principles such as informed consent, disclosure and confidentiality. In addition, the Batho Pele principles should be reinforced. Health care workers require special training on the process and impact of stigmatisation. Finally, human rights training for them should focus on basic principles and the Bill of Rights.

- A plain language version of the Bill of Rights should be produced and made available in local languages. In addition, plain language versions of the major legislation that protects and promotes the human rights of those living with HIV/AIDS should be made available to the community.

- The mobile units used to service rural areas by the Department of Social Welfare and the Department...
of Home Affairs, can be used by organisations such as the South African Human Rights Commission to distribute plain language versions of the Bill of Rights or to do outreach on the services that they offer, the complaints they handle, and the processes that they follow.

- The training of AIDS service organisations in human rights is crucial. People involved in home-based care are an important resource to access community members and can be used to assess whether or not human rights violations are taking place. The training must be comprehensive and must include information on what to do when caregivers come across human rights violations: what processes should be followed, and what organisations should be approached? This training would have to include information on the specific Chapter 9 institutions of government, including for example, the South African Human Rights Commission, the Commission on Gender Equality and the Public Protector.

- Community based human rights “champions” should be trained. These champions could be ward committee members or other community leaders, who would be visible enough so that people would know that, should they have a human rights-related query or concern, they could approach the champion for assistance or a referral to the appropriate agency or organisation.

6.3 Suggested areas for future research

- Further research is required to examine the impact of the area being part of a cross-border municipality. In addition, further investigation of the roles of the local government, ward committees and the LAC is highly recommended.

- Research is required on the role of public health care institutions and their impact in the community. It is obvious at present that there is much misunderstanding between the community and health care workers about this issue, and this needs to be investigated more fully.

- Further research is needed to determine whether access to ART impacts on stigma and discrimination, i.e. whether PLHAs are more willing to allow themselves to be subjected to gossip in order to access treatment, or does gossip and stigma decrease because there is no longer an association of HIV with death?

- It would be useful to conduct research on the role of social grants in getting people to come forward for HIV testing, and whether or not community members are engaging in high-risk behaviour in order to access social grants.
CHAPTER 2

Beyond ‘bitches and prostitutes’: Folding the materiality of gender and sexuality into rights-based HIV/AIDS interventions

Amanda Alexander* and Mandisa Mbali*

Amanda Alexander is a Visiting Researcher and Mandisa Mbali a Research Fellow at the Centre for Civil Society, School of Development Studies, University of KwaZulu-Natal
1. Introduction: Towards a Gendered Analysis of HIV/AIDS and Human Rights

"... human rights abuses are best understood from the point of view of the poor."¹

This chapter offers a gender-based analysis of the findings of the Tselelopele Research Project. It is based on a close reading of the report and interview transcripts provided to the authors by the study co-ordinator. The Tselelopele study aimed to analyse HIV/AIDS-related stigma and discrimination and the impact of the human rights discourse on responses to the AIDS epidemic in Hammanskraal and Temba, two adjacent peri-urban and rural areas in Tshwane municipality in Gauteng, South Africa. Towards this end, it aimed to:

• establish which organisations and institutions were promoting human rights locally;
• examine the impacts of human rights at individual and community levels, particularly in terms of service delivery; and
• design interventions (such as a training manual on AIDS and human rights) to make human rights more accessible to people living with HIV.²

A careful reading of the interview and focus group transcripts reveals that, as in other parts of South Africa, gender relations in Hammanskraal and Temba are closely interwoven with prevailing material conditions. To be more precise, high rates of unemployment often drive women into commodified and commercial sexual relations. Moreover, HIV-positive women in these communities are stigmatised as being prostitutes, or “loose women”, or as having “invited” HIV infection to claim access to social grants. In order to reduce women’s greater social risk of contracting HIV and their greater vulnerability to bearing the socio-economic impact of HIV/AIDS, the post-apartheid government’s failure to fully realise women’s socio-economic rights must be addressed. In a broader sense, we argue that women’s heightened risk of HIV infection and greater vulnerability to bearing the impacts of the epidemic reveal that gender power operates at both discursive and material levels in these communities. In her 1997 book EnGendering AIDS, Tamsin Wilton highlights gender and material inequality as the two most significant (and inextricably linked) social factors contributing to the epidemic’s growth. As she argues:³

Women’s relative powerlessness in heterosex is largely determined by material inequalities that obtain between women and men ... material inequalities that give rise to and are in turn supported by cultural and ideological constructions of gender.

In light of the links between socio-economic conditions and gender inequality, promoting “human rights literacy” divorced from support for civil society mobilisation in the community is insufficient.

We argue that barriers to realising rights are fundamentally socio-economic in nature. Working from Paul Farmer’s assertion that “the absence of social and economic power empties political rights of their substance”;⁴ we propose that in order to realise human rights, we must bear in mind that women’s disproportionate vulnerability to contracting HIV infection and to bearing the impact of the epidemic is closely related to a failure on the part of the government to fully realise women’s socio-economic rights. We also contend that these rights will only be claimed by grassroots civil society activism by poor communities, which ought to be supported on multiple levels by progressive intellectuals.

² Ch 1 para 2.2 above.
⁴ Farmer, note 1 above 16-17.
2. “Bitches and Prostitutes”: The Materiality of Gender and Sexuality

In many of the interviews and focus groups conducted as part of the study, community members cited unemployment as a key problem in Hammanskraal, in some cases even highlighting it before discussing HIV/AIDS. Recent research has shown that high rates of unemployment are endemic nationally and that young African women are the social group most likely to be unemployed. In the introductory section of this paper we argue that the commodified multiple partner relationships (which usually involve younger poorer women being involved with older wealthier men and which render women vulnerable to HIV infection) described in focus groups are closely related to high levels of young African female unemployment in the community and in the country as a whole. This demonstrates that gender inequality works at material and discursive levels which cannot be addressed through “human rights education” alone.

It is estimated that 37% of South Africans are unemployed. Moreover, Charles Meth and Rosa Dias recently argued that in 2005 there could be as many as 4.5 million more people living in poverty than in 1995. If this calculation proves true, this figure is shocking, given that South Africa is one of the top 50 economies in the world. Indeed, this high figure can only be due to the fact that South Africa is one of the most unequal societies in the world – characterised by enormous racial stratification – with an extremely low ranking in the UNDP’s Human Development Index as a consequence. South Africa is also one of the few countries whose rankings have slipped since 1995.

Persistently high rates of unemployment seem to be at the heart of poverty and inequality in post-apartheid South Africa. Of relevance to our gendered analysis of AIDS and drawing on the 2001 Labour Force Survey, Anna McCord has argued that women encounter significantly higher levels of unemployment than men, in urban, peri-urban and rural settings. Furthermore, she goes on to argue, given the high number of female-headed households in South Africa, this has negative implications for the overall well-being of poor communities. Female unemployment is worst among non-urban African females, 47.2% of whom are unemployed. Unemployment is also heavily concentrated among young people under the age of 35 years.

Gender and sexuality in Hammanskraal and Temba need to be viewed as operating at both discursive, cultural levels and material, socio-economic levels. To be more precise, as Paul Farmer has argued in discussing commodified and commercial sex in Haiti, human suffering is structured by economic factors in ways that constrain agency. Similarly, individuals in Hammanskraal and Temba make choices under severe social and economic constraints. Given that research shows that most South Africans are aware of how HIV is transmitted and how it can be prevented, some observers are puzzled that HIV infection rates continue to rise. (Or, more often, observers will jump to blame individuals or their cultures in an over-generalised, exoticising and decontextualised way.) Knowledge is not enough, however, when individuals’ options and choices are constrained by their social and economic positions. Within the framework of most HIV/AIDS prevention strategies and human rights literacy initiatives, there is an implied theory of the subject who makes choices only on the basis of knowledge. This ignores that gender inequality and poverty can be under-

8 Ibid.
9 McCord, note 5 above.
10 Ibid.
11 Ibid, 48.
stood as being structural violence and the fact that sexual identities – and the choices permitted to individuals – are part of a social fabric. In order for men and women to break out of gendered roles which constrain their sexual decisions, there need to be collective ways of re-organising social norms, meanings and underlying beliefs. As Tamsin Wilton argues in relation to women’s sexual choices: “To make the healthier choice the easier choice demands no less than the absolute eradication of the institution of male supremacy.”

Until social and economic inequalities are addressed, individual agency will continue to be constrained. This means that in Hammanskraal and Temba, individuals will continue to engage in commercial and commodified sex, for example, despite their knowledge that such actions may put them at risk of contracting HIV.

Recent epidemiological and ethnographic literature has shown how commercial and commodified sex is a key factor driving the growth in new infections. Like Hunter, we would argue that the high unemployment rate is a key catalyst for the growth in relationships involving exchange of sex for gifts or money in South Africa. As he has shown, while some of these relationships are about survival and subsistence, others are about young women’s desire to consume and be fashionable: in the words of some of the study’s key informants, some young women want to be seen with men driving BMWs, want to have sex with men in nice hotels and to eat Nandos; in return men want sex, usually without using condoms. At a discursive level, this type of behaviour is associated with HIV-positive women in a deeply gendered and stigmatising way: they are seen as “bitches” and “prostitutes” (izifebe) or “loose” women who drink alcohol and behave “inappropriately”.

Melding material and discursive readings of gender, Mark Hunter has shown how gendered high unemployment rates have fostered a decline in marriage and a rise in commodified multiple partner relationships in KwaZulu-Natal. Hunter demonstrates how this discourse of a sexual double standard is often applied to these relationships, which lionises men with multiple partners as being successful with women, and stigmatises women with multiple partners as being prostitutes. Moreover, high unemployment rates also shape masculine identities and models of sexuality. In a peri-urban community in South Africa, Hunter shows how high rates of unemployment have eroded traditional lobola payments prior to marriage and how marriage rates have rapidly declined in KwaZulu-Natal owing to couples no longer being able to afford setting up a homestead (an umuzi).

In order to prove their “manliness” in a context of high unemployment, some men resort to having multiple sexual partners (often in commodified ways) and beating female partners who are seen to be “disrespectful”. The impact of sexual violence on South Africa’s AIDS epidemic was recently demonstrated by a study published in The Lancet which showed that women with violent and controlling partners are at significantly greater risk of HIV infection.

14 Wilson, note 3 above 52.
16 Hunter, note 15 above.
17 FG3.
18 FG8: see ch 1 para 4.2.2.2.
19 Hunter, note 15 above.
20 Ibid.
21 Lobola is a Zulu custom in which a man must pay cattle to a woman’s family in order to marry her.
22 Hunter, note 15 above 140.
Addressing the inequalities in relationships between men and women is fundamentally about addressing both material and discursive inequalities between men and women. Sexist discourses such as the sexual double standard need to be addressed, but so does the fact that more women than men are unemployed and that women often earn less than men. In this regard, educating women with a manual about their rights (as stated in the Bill of Rights), as the study aims to do, is an insufficient approach to addressing the material aspects of gender, underscoring the need for an understanding of gender as operating at material and discursive levels.

Women’s right to gender equality can only be made real through addressing their need for economic empowerment. In this regard, the report mentions that for many of the informants living with HIV disability grants are “extremely important for survival”, a finding which is echoed in the interviews with various informants. Given the importance of social grants to the livelihoods of poor women, we support the government’s extension of the child support grant and believe that the introduction of a basic income grant would substantially assist in the alleviation of poverty.

In terms of this, we reject gendered, stigmatising discourses, such as the views expressed by health care workers and social workers interviewed as a part of the study that recipients of social grants are becoming willfully infected with HIV in order to access disability grants or that young women are becoming pregnant to access grants. We also recognise the genealogy of these stigmatising discourses in racist and sexist notions of “welfare queenism” first espoused by social conservatives in 1980s America. Indeed, these discourses may be a lightning rod for the expression of conservative social anxieties about the decline in marriage and many young women’s increasing sense of their ‘rights’ to fashion their own sexuality, access the grants and control their own reproductive health, contrary to the wishes of older, more conservative members of their families and communities. Illustrative of this, male members of a youth social club interviewed as a part of the study argued that young people were misusing freedom of speech to engage in sex and that “their parents were unable to comment on their behaviour”. Material realities shape gender in ways that fuel the AIDS epidemic. A high unemployment rate and income inequalities between men and women have promoted commodified, multiple partner sexual relationships. We would argue that given this reality, progressive feminist researchers must advocate for wider access to social grants in order to fully address gender inequality and reject conservative, gendered discourses which stigmatise poor young women who are grant recipients.

Less public than stigma and discrimination regarding sexual behaviour, but no less of a strain on women, is the disproportionately high burden placed on women to care for family members who are suffering from AIDS-related illnesses. The gendered care burden was not discussed in the report, even though it was highlighted that many informants were resistant to visiting hospitals – even in the terminal stage of AIDS – due to the poor treatment they might receive at public facilities. Since the South African government has not responded to the HIV/AIDS epidemic by ensuring that hospitals have adequate resources to care for HIV patients, there has been a shift from hospital-based care to home-based care for these patients. This often means that young women are forced to drop out of school to care for a sick family member, and that elderly women become sole providers for grandchildren who have been orphaned due to AIDS. The caregiver role places physical, emotional, social and economic stress on women, all of which is

24 Ch 1 para 4.5.1; FG3, FG4, FG8.  
25 FG5 and FG7.  
26 FG10.  
27 Ch 1 above para 4.4.3. 
exacerbated by social constructions of the “maternal” role. Emotional stress is compounded when women caregivers are prevented from voicing their problems because socio-cultural norms make it improper for them to complain. As “givers” they are expected to be stronger than the “receiver” at every moment, and this places great stress upon their own physical and mental health. Because of the inadequacies of the public health system, gendered inequalities are thus perpetuated in this way in the face of the HIV/AIDS epidemic. For some women, the stigma of being considered insensitive to the plight of the sick around them or, in other words, of being “bad mothers” is just as threatening as that of being deemed a “loose woman” or a “bitch”. This discursive reality must be addressed by tackling the material conditions which fuel and exacerbate it.

3. Problems With Rights
Talk From Above

We have begun with a discussion of material realities because, as we will argue, these are the primary sites where human rights take on concrete meaning. Chandra Talpade Mohanty argues that a useful feminist analysis of global capitalism must begin from the practices and knowledges of marginalised women; from this social location we can “read up” the power structure and generate an analysis that would be impossible to achieve from a perspective atop profit-based hierarchies. Similarly, international human rights discourse and initiatives – which are often framed within institutions that are deeply enmeshed in market-based, profit-driven, patriarchal power – fail to grasp unique and complicated local realities. Thus these initiatives fail to foresee the specific material conditions that will keep rights out of the reach of marginalised women.

With this critique in mind, it is troubling that the report’s definition of a rights-based approach to HIV/AIDS is largely based on international treaties. The report argues that, “states’ obligations to promote and protect HIV/AIDS-related human rights are defined in existing international treaties”, and goes on to list nearly twenty rights.

Recognising the importance of 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, developed in consultation by UNAIDS and the Office of the United Nations High Commissioner for Human Rights, with input from various stakeholders from the private and public sector (including NGOs, CBOs, academics, people living with HIV/AIDS, etc) ...

In reality, these international bodies and meetings are usually weakly consultative from gender, race, class and geographic perspectives. The report references (albeit in a footnote) the Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa (AMICAALL) on the importance of local-level strategising and action. The report states that “AMICAALL acknowledges that ‘national government officials may be too far away to hear voice of ordinary citizens [sic] ... Local problems need local efforts to resolve them, and the greatest impact of the epidemic is felt in communities”.

Despite acknowledging the expressed needs of local authorities to the contrary, the report reverts back to international and national level human rights discourse as the solution to local problems.

---

29 Akintola, note 28 above.
30 Akintola, note 28 above.
32 Ch 1 above para 2.1. See, however, also para 2.2 where the South African Bill of Rights is referred to.
33 Ch 1 above para 2.1.
34 Ibid.
35 Ch 1 above para 3.1 (footnote 11).
36 We recognise that local authorities also often fall short of representing the needs of women, but this reference is the closest that the report’s introductory sections come to the local level.
The lack of participation by those who are conceivably most in need of the protection that human rights may offer has obvious negative implications for the local-level realisation of rights. In her study of UN efforts to promote human rights in Africa, Zoë Wilson has built upon fieldwork in Angola, Botswana, Namibia and Tanzania, and has shown that the combination of weak consultation with human rights “victims” and the reliance upon patriarchal states to enforce rights denies women their rights at local levels.\(^\text{37}\) Citing Martin Shaw’s 1999 study of human rights and the experiences of Kurdish refugees, Wilson argues that:\(^\text{38}\)

The ‘global society’ that struggles to end egregious human rights violations only dimly and inadequately corresponds to a cosmopolitan democratic model ... Rather, it tends to rely on indirect representation of ‘victims’ co-opting their voices through media images and sound bites, repackaging their concerns for western consumption. ‘Globalist ideas may represent inclusive global interests in an ideological sense, but how far do they actually involve people across the globe?’

Human rights were thus conceived with minimal knowledge of local-level situations and so – since it is here where human rights must take on meaning through assertion and recognition – it becomes that much more difficult for abstract rights to adequately serve the specific needs of the most oppressed. The challenge is amplified in the case of women’s rights. Wilson draws on the work of several feminist authors who have argued that faith in the state as a neutral protector of rights is misplaced. Since states are “patriarchal, hierarchical, [and] militarised entities”, they inevitably create and perpetuate power relations that are antithetical to realising the rights of women.\(^\text{39}\)

Despite the problems of weak consultation and an over-reliance upon patriarchal states as enforcers, human rights still hold undeniable power in the minds of many oppressed people. There is an authority in human rights talk, but unfortunately it is too often an abstract, inaccessible authority, as highlighted in the report and focus group interviews.\(^\text{40}\) At a national level, in post-apartheid South Africa, the Bill of Rights in the country’s Constitution is the most important human rights instrument. However, human rights court challenges around HIV/AIDS (such as the Treatment Action Campaign \textit{v the Minister of Health}) can be extremely costly and, therefore, could be inaccessible to many poor people living with HIV. This is especially the case in Hammanskraal, where the study reveals that the University of Pretoria-run Law Clinic has received no money from the Legal Aid Board and so tells potential clients to go to a private attorney or “carry on by themselves”.\(^\text{41}\)

Despite their inaccessibility and instability, Patricia Williams argues that rights carry exceptional importance for oppressed people. She writes:\(^\text{42}\)

In discarding rights altogether, one discards a symbol too deeply enmeshed in the psyche of the oppressed to lose without trauma and much resistance. Instead, society must give them away. Unlock them from reification ...

According to Williams, oppressed people have a unique relationship with their rights, as their livelihood depends on the formality that rights impose on interpersonal interactions and the enforceability that rights carry. Particularly for black women, who are so often assumed to be (and dismissed as) “unreliable, untrustworthy, hostile, angry, powerless, irrational, and probably destitute”, invoking rights clarifies boundaries and – through very personal empowerment – is a way of defining the self.\(^\text{43}\)


\(^{38}\) Wilson, note 37 above 46-47.

\(^{39}\) Wilson, note 37 above 46.

\(^{40}\) Ch 1 above para 5.

\(^{41}\) K11. This was an interview conducted with a representative of the University of Pretoria’s Legal Aid Clinic in Hammanskraal. See Appendix 1.


\(^{43}\) Williams, note 42 above 83, 85.
When our gaze is focused on the level of international human rights discourse, we fail to grasp unique and complicated local discourses. Because of the operating assumption that human rights discourse is the best approach to serve these areas, and without an understanding of complex local realities, the report gives the unfortunate impression that families and communities are merely things that people must be protected from (by the government and rights language). The disintegration of familial relations is not put in context, as there is only one sentence devoted to describing the motivations behind families’ actions: “Families were worried that the HIV status of their family members reflected badly on them, that they had failed to raise their children with proper social and moral values, and that this impacted on the treatment of the family in the community”.

The report’s analysis of faith-based organisations suffers from the same problem; no efforts are made to understand the motivations of the congregation that is mentioned. Rather, claims go unexplored. Again and again, we hear that the community “lacks knowledge”. This is the focus of the section entitled “Is a human rights approach at community level sufficient?” and of the report’s recommendations and conclusions.

Throughout the report, real differences in opinion, values and perspective (i.e. between patients and health-care workers, police and citizens, traditional leaders and women, local government and the community, etc) are glossed over; community actors are routinely dismissed as being ignorant of human rights and documents such as the Bill of Rights. However, if the goal is to make a human rights approach truly stick within a community and serve it, we need to recognise that this is not simply a matter of ignorance, but that human rights documents, especially the Constitution, are at discord with many South Africans’ values and norms. As we argue in the next section of the paper there is clearly an ongoing set of debates regarding gender equality and sexuality taking place at local levels around the country. South Africa’s Constitution is more progressive than many of its people, particularly on issues of women’s rights. So, it will take much more to “make rights real” than telling people what the Constitution says and how it can (theoretically) be enforced. Overall, we need to be concerned not just with how well human rights language is trickling down to communities (the concern of this report), but also – especially with regard to women – how well community experiences, languages, and interpretations are reflected and addressed at all levels of government.

To ensure that international expectations of human rights meet local demands, researchers and those concerned with promoting human rights need to seriously engage with local norms and values (that is, with local culture itself). On this point, Abdullahi An-Na’im and Jeffrey Hammond, drawing on their work in Kenya, have recently argued that culture and local discourse profoundly affect the articulation and implementation of human rights. This is not to say that local culture is static: as they go on to argue, culture is constantly changing through the work of non-elite actors who are “change agents” in altering their own culture. Indeed, “The best way to get a universal idea accepted locally is to present it in local terms, which can best be done by local people.” Similarly, Celestine Nyamu-Musembi has argued that local administrative bodies and informal institutions will have to become sites of debate for greater realisation of gender equality in African contexts. She goes on to argue that this can only happen through greater involvement of women in local institutions, particularly of a traditional nature. In the next section, we will turn to a discussion of rights discourses and realisation strategies at the community level.

44 Ch 1 above para 4.6.1.
45 Ibid.
46 Ibid.
47 Ch 1 above para 5.
50 As above, 16.
4. Gender and Rights Talk From Below

“It’s bad because it gives the women more power than the men.”

– A traditional leader on the Bill of Rights.52

There is a wealth of ethnographic evidence that young people are invoking rights-based discourse on a regular basis in urban, peri-urban and rural contexts in South Africa. Therefore, we would question the report’s assertion that not having actually read the Constitution’s Bill of Rights means that poor people in the community are broadly “ignorant” about its contents and that this is the fundamental barrier to the community claiming their rights.53 The legacy of Bantu Education in South Africa means that many poor Africans have had limited access to quality education, however, that does not mean that they do not orally discuss the Bill of Rights’ concepts. For instance, just as some of the study’s informants complained about “women’s rights” in the Constitution, several other informants complained about poor access to health services and social security, which suggests that poor people have a fairly clear sense of what they are socio-economically entitled to, even if this is not framed in terms of specific articles of the Bill of Rights.

For instance, participants living with HIV in one of the study’s focus groups pointed out how being poor limits the right to access to health care.54

F2: ... you find that you go to Jubilee [Hospital] and you are very sick and you don’t have R17 to pay for the treatment and they will send you back home because you don’t have money.
M2: This hurts you ...?
F2: Yes.
F1: And we are poor.

In recent ethnographic research conducted in rural KwaZulu-Natal, Sarah Mathis showed that human rights discourse has become ubiquitous in post-apartheid South Africa, even in the most impoverished rural communities. She has argued as follows:55

With the end of apartheid, talk of rights has proliferated through the medium of the radio and school curriculums. No longer the discourse only of elites, talk about rights and concern over the preservation of cultural autonomy has spread even to rural women in KwaZulu-Natal with some of the lowest levels of access to information and education in the country.

Mathis goes on to show how older women see younger women as having been inappropriately empowered through human rights discourse and thereby “losing their culture” through having children out of wedlock.56 As the above quote from a traditional leader shows, some community members may interpret human rights discourse as having disproportionately empowered women, with negative outcomes.

Similarly, Mark Hunter has argued that South African young people are increasingly aware of their ‘rights’ post-1994.57 He has also shown how young people have taken on board rights-based messages with differing consequences in terms of gender and sexuality. Some young men wear T-shirts and join groups opposing abuse of women and children.58 Similarly, some women draw on modern media aimed at and readily available to township youth to assert the merits of monogamy, indeed Hunter argues as follows:59

Some women can tie the ‘modern’ images of ‘girl power’ to discourses of ‘rights’ and to the threat of AIDS, to strongly assert the merits of monogamy. Bolstered by discourses of women’s ‘rights’ in

52 KI19.
53 Ch 1 above para 1.5.2.
54 FG2. This was a focus group conducted as part of the study.
56 Ibid.
58 Ibid.
59 Hunter, note 57 above 142.
the post-apartheid period, some women now oppose with new energy an isoka’s (a man with multiple partners) right to secure more than one sexual partner.

Conversely, he goes on to argue that another group of women is invoking rights-based discourse to challenge the sexual double standard by stating that things are now “50-50” between men and women and that they also have the “right” to “benefit” from having multiple partners.60

More importantly, in terms of our focus on gender, HIV/AIDS and human rights, there are contested discourses in Hammanskraal and Temba regarding what makes women vulnerable to HIV infection, some of which reinforce sexism, and others which challenge it. Some male informants made stigmatising remarks that women living with HIV were often prostitutes who had multiple partners to access money and gifts.61 However, others argued that married women or women in long-term relationships were vulnerable to HIV infection, as their partners were not faithful and refused to use condoms.62 This existence of different and conflicting views on the relationship between gender and HIV/AIDS – some more stigmatising than others – suggests that there is scope for encouraging people within the community to promote gender equality within local forums in accessible ways.

We argue that the promotion of gender equality needs to happen through civil society action from below and that changing and contested views on the relationship between gender and HIV/AIDS in the community should provide a basis for such action. The report mentions the lamentable lack of organisations like the Treatment Action Campaign (TAC) in Hammanskraal and Temba, a lack which is probably due to the fact that, like many civil society organisations, the TAC is mainly an urban and peri-urban organisation and has only a patchy presence in rural areas.63 The absence of the TAC in these communities is a fair criticism, but the report neglects to make a far bigger point about the organisation: that the TAC has been a successful, nation-wide grassroots campaign for realising the right to access antiretrovirals for prevention of mother-to-child-transmission, post-exposure prophylaxis following sexual assault and for use as part of combination drug therapy.64

In its activism, the TAC has recognised that human rights violations need to be understood at the macro, structural level, not merely as an effect of “ignorance-based” local stigmatising discourses alone. The TAC’s campaign has shown how women’s subordinate position in society is closely related to the operation of multinational corporations, global capital and South African government health policy, and how an analysis of sexism needs to move beyond a mere micro-level discursive analysis of the operation of sexism. Moreover, in terms of Farmer’s description of second generation rights as giving meaning to first generation rights,65 the TAC has shown how organisations pushing for second generation rights can give meaning to political rights such as freedom of expression, speech and assembly.66 As we will discuss further in the conclusion, TAC also forms part of a growing number of new social movements in South Africa through which poor communities are increasingly claiming their socio-economic rights.67

60 As above, 143.
61 FG10.
62 FG1, FG3 and FGB.
5. Ethnography and Women’s Realities: Towards a Meaningful Notion of Rights

The Tswelopele study’s under-emphasis on the role of structural and material factors in bolstering gender inequality can be traced to some of the study’s key methodological flaws. Many of these flaws are inherently gendered. These oversights include the privileging of international human rights discourse (which is usually weakly consultative from the perspectives of gender, race, class and geography) over community experience and discourse, the use of a male translator, the failure to disaggregate unemployment, income and education figures by gender, and the lack of an ethnographic lens. These methodological flaws inhibit the study’s ability to describe gender inequality and the operation of gender power in the Hammanskraal and Temba.

Throughout the study, effort was not made to see how community and human rights discourses actually interact. Since the researchers operated under the assumption that the community needed a human rights manual, community discourse was measured against international and national human rights discourse, and was found to be irredeemably flawed. The goal, then, was to replace existing discourse with hegemonic human rights language. An ethnographic study which included observation and interaction with community members in various settings over time, with an eye towards modes of communication and self-representation besides the stilted language of interviews (including silences, songs, dances, gestures, glances and tears) might have revealed the ways in which rights are being vernacularised. Rights are being “made real” within existing realities – the challenge for human rights researchers and promoters, then, is to understand the nuances and contradictions of those community contexts.

Ethnographic methods can reveal a far greater amount of nuance in understandings women’s experiences of the complex relationship between HIV/AIDS and gender. Due to the gender dynamics of the focus groups which included both men and women (and which were translated by a man), we do not gain a holistic sense of Hammanskraal and Temba women’s experiences. Even the data collected from one-on-one interviews may suffer from gendered flaws. Nthabiseng Motsemme warns of the danger of relying on verbal language alone to understand women’s experiences. The experiences of women who have been stigmatised, violated, and discriminated against (often on a daily basis) have complex meanings which can rarely be articulated. This is especially so in the cases of stigma and discrimination, which often rely on a breakdown in communication or a ‘shunning’ to make themselves clear. In her study of women’s silences at the Truth and Reconciliation Commission (TRC) hearings, Motsemme has argued:

It became clear that it was not only silence that should be invested with complex meanings, but also dreams, prayers, gestures, tears, sounds, smells, tastes and the flesh. These were the places that oppressed women often housed their memories and thus grounded meanings of violating events.

By ignoring non-linguistic sites, we can also ignore those who – often because of material conditions – have difficulties putting their experiences into words in certain research-based settings, particularly where there are gender and class differences between the interviewer and interviewee. This blindspot is indicative of a deep-seeded, gendered bias in many forms of qualitative and quantitative research methodology. Motsemme points out that more ethnographic research – which relies on multiple interpretative sites, including the cultural and emotional realms – are cast as “feminised” and, for this reason, are considered secondary to “objective” analyses offered by other qualitative and quantitative research methods. Thus, the lack of an ethnographic lens is a gendered flaw, with gendered consequences.

68 See Appendix 2 to original Tswelopele report.
70 Motsemme, note 69 above 5.
As a result, we come away with a skewed picture of women and gender relations in Hammanskraal and Temba. This relates to a broader negative outcome of flawed methodology, which is that the report makes improbably broad – and dangerously uncontextualised – cultural generalisations. It makes sweeping statements such as: “… traditional healers believed that AIDS was curable…”71 and “When someone died of AIDS it was attributed to witchcraft.”72 These statements are not discussed in terms of other ethnographic literature on beliefs about witchcraft and HIV/AIDS in Gauteng73 or even older ethnographic literature discussing the role of traditional healing in African societies in the same province.74 In the same vein, it needs to be recognised that traditional healing is a changing profession and that there is by no means consensus amongst traditional healers over diagnosis, treatment and cure of different diseases. Thus a highly complex and contested belief system and profession appears uni-dimensional in the report. This has larger, potentially quite dangerous implications for approaches to confronting HIV/AIDS and promoting human rights.

Anthropologists are not even entirely in agreement about how commonly the “witchcraft theory” is invoked by traditional healers to describe HIV/AIDS. For instance, while Adam Ashforth has argued that witchcraft theories of purposeful use of malign cosmic interpersonal forces are often invoked to describe HIV/AIDS,75 medical anthropologist Edward C Green has argued that clear dichotomies between Western biomedical models of understanding AIDS (relying on germ theory) and African traditional models in Southern Africa may be misleading.76 In contrast to Ashforth, Green has argued that Western germ theory-based paradigms bear similarities to some African traditional healing paradigms which conceptualise HIV/AIDS as caused by non-witchcraft-related, pollution-based, or naturalistic, causes. Moreover, while the vast majority of Africans consult traditional healers, they also use public health facilities, suggesting a “hedging” of bets and a complex interaction between different sets of beliefs around health and healing among members of communities such as Temba and Hammanskraal.

We would caution against poorly contextualised and unproblematised readings of the relationship between stigma and certain cultural beliefs, as this can lead to an exoticising of the “other”. Paul Farmer argues that we cannot sufficiently analyse human rights violations solely in terms of “cultural difference” or “otherness”, but that we also need to consider the human rights effects of poverty and inequality.77 Furthermore, without contextualising references to witchcraft and exploring their meanings in a South African setting through discussing existing ethnographic literature, the report invites its readers to assume that informants are using the term with the same loaded gender connotations that it carries in Western contexts. Once again, ethnographic research would have provided far more insight on community perceptions and, in turn, the experiences of women.

6. Conclusion

A gendered, human rights-based approach to HIV/AIDS must involve addressing socio-economic structural inequalities. In this regard, we question the report’s problematisation of barriers to human rights-based approaches to HIV/AIDS, which views these communities’ “ignorance” about human rights as the key problem and “human rights education” as the solution. The report fails to truly engage with the materiality of gender and sexuality and only glibly notes that it is questionable whether it is possible to make rights real in an environment of poverty and unemployment.78 In contrast, recent ethnographic literature demonstrates that young people in poor

71 Ch 1 above para 4.6.8. (The inference of a sweeping generalization is perhaps an overstatement as the report obviously provides a summary of interviews, and does not lay claim to present generally applicable insights – editor.)
72 As above, 29.
74 Schapera, I (1953) The Tswana.
75 Ashforth, note 73 above.
77 Farmer, note 65 above 48.
78 Ch 1 above para 6.1 (where the limitations of “just informing people about their rights” are also acknowledged – editor).
communities invoke rights-based discourse regularly in diverse ways. Contrary to the report’s framework, we argue that HIV/AIDS relates to gender in both discursive (such as stigmatising discourses which frame HIV positive women as being “loose”) and material ways (such as poorer younger women sleeping with older wealthier men in exchange for gifts or money and women disproportionately bearing the burden of caring for terminally ill family members) – ways which conspire to put poor African women disproportionately at risk of HIV infection and of bearing the socio-economic impact of the epidemic.

There are key methodological flaws at the heart of the study which inhibit its ability to provide more in-depth descriptions of the communities from political, historical and cultural perspectives. This in turn inhibits the study’s ability to provide a fully-rounded picture of the relationship between AIDS and gender: at the most apparent level, gender-mixed focus groups and interviews may have inhibited women’s voices coming through. At a deeper level, the report’s failure to contextualise “witchcraft” explanations of HIV/AIDS in terms of ethnographic literature and a reading of informants’ broader “life-worlds” leads to exoticised explanations of HIV/AIDS-related stigma. At the same time, the report overlooks more banal, but cogent, explanations of HIV/AIDS and gender as related to poverty and inequality, which lie at the very core of everyday violations of poor women’s fundamental human dignity.

Indeed, a careful reading of the Tseloepole study report and of the study’s transcripts of interviews and focus groups reveals that, as in other rural and peri-urban locales in South Africa, gender relations in Temba and Hammanskraal are closely tied to prevailing material conditions. Overall, there are high unemployment rates in such communities and nationwide these rates are higher for women than men. This material reality draws women and men into commercial and commodified sexual relationships, which place women at greater risk of HIV infection.

Since barriers to realising rights are fundamentally socio-economic in nature, more is required than having a researcher assist in training “community-based human rights ‘champions’” in “human rights literacy”. We are advocating for a model where the converse is true: where researchers start from the position that they have a great deal to learn from poor people about how human rights function in practice, especially given the existence of ethnographic literature demonstrating a wealth of knowledge and discussion about human rights in rural, peri-urban and urban communities. Researchers should also support grassroots struggles for the realisation of socio-economic rights. We agree that such communities might need greater information on HIV/AIDS prevention and treatment and that stigma based upon a lack of this type of basic medical information is at the heart of many incidences of localised HIV/AIDS discrimination. However, we question whether this is a sufficient explanation of the structural barriers to the full realisation of the human rights of poor women infected with and affected by HIV/AIDS.

Community education through the dissemination of a manual is insufficient, as this approach theorises human rights as being primarily enforced “from above” through laws interpreted with the assistance of researchers and lawyers, not as claimed “from below” by community-based, civil society groups demanding socio-economic justice. We must not underestimate the historical and socio-political agency of South African community-based civil society actors in confronting the adverse socio-economic realities they face. In terms of this, in a similar
vein to Nyamu-Musembi, we argue that such projects ought to promote greater and more meaningful participation of women in local administrative bodies and institutions and provide forums for the discussion of material and discursive barriers to realising gender equality.

The premise should not be that communities need to be educated about international human rights agreements (which are weakly consultative and depend on the goodwill of patriarchal governments to implement) and the Constitution (which requires expensive court action to ensure legal enforcement and requires the mediation of academics and lawyers). Instead, we argue that progressive feminist academics should take as a point of departure Farmer’s assertion that human rights are best understood from the point of view of the poor. This is especially the case given that we are convinced that poverty and inequality need to be challenged for the realisation of full gender equality. If we take this as our point of departure, we support socio-economic justice-based demands of new social movements made up of poor people. Moreover, we recognise that the invocation of human rights-based discourse to forward these struggles is only one approach, which may not be strategically preferable in all instances.

While we need to view structural inequalities as shaping the epidemic in these two locales we are also calling for a reinsertion of political, cultural and social agency into the picture. The report’s title, “If you (be)come HIV positive, you will lose your human rights”, deals with a very narrow idea of civil and political rights, while in reality, most people who are HIV positive have already been wronged by socio-economic injustices. In response to this, many poor HIV-positive people have joined new social movements such as the TAC, trying to reclaim their human rights. Having or losing human rights should not be made into a dichotomy between HIV-positive and HIV-negative people. Rather, communities with poor health care facilities, the majority of its citizens (especially women) unemployed, and few opportunities for jobs and higher education, are already living in social environments that are generative of socio-economic injustices which have fueled the AIDS crisis. This suggests that to fully promote more comprehensive human rights-based approaches to the HIV/AIDS crisis, researchers ought to fold structural, socio-economic-based factors into our interpretations of the relationship between HIV/AIDS and gender.

81 These social movements have demanded reforms such as: decommodification of water and electricity for poor people; an end to cost-recovery-based evictions; comprehensive, universal and free access to all AIDS medicines, as part of radically increased spending to strengthen the public health system; the introduction of a universal Basic Income Grant; and an accelerated gender-progressive and non-marketised approach to land reform.
CHAPTER 3

Disclosing in an age of AIDS: Confidentiality and community in conflict?

Does her status threaten you?

Frans Viljoen
AIDS and Human Rights Research Unit, University of Pretoria
1. Introduction

In 2004, the Centre for the Study of AIDS at the University of Pretoria conducted a study on HIV/AIDS stigma and human rights in the peri-urban and rural communities of Temba and Hammanskraal near Pretoria (now Tshwane). Interviews were held with the members of 15 focus groups (comprising 116 people) and 23 key informants. On the basis of these interviews, this monograph analyses the interface between disclosure of HIV status, the right to privacy (on which claims to confidentiality are based), and stigma on the basis of HIV/AIDS. In so far as generalisations are made, they are presented in the consciousness that stigmatisation may differ according to context.

“Privacy” is defined as the “state or condition of being withdrawn from the society of others ...”. The right to privacy, accordingly, is an individualistic right, the ultimate right “to be left alone”, indicating an individual self separated from collective identity and rooted in personal preference. The right to privacy is often associated with claims pertaining to “nobody’s business but mine”, which may include the possession of pornography or decisions concerning sexual relationships. The very definition and the application in case-law posit the right to privacy in opposition to the collective concerns of society.

In an era of HIV and AIDS, other notions of privacy have been entertained. These depart from a premise of a collective interest or stake in private knowledge, and give rise to the notion of “shared consent”. In terms of a World Health Organisation Fact Sheet, “shared confidentiality” is “confidentiality that is shared with others”, such as family members, loved ones, care-givers and trusted friends.

According to the Fact Sheet, sharing confidentiality is in the discretion of a person who has been tested for HIV. The notion of “shared confidentiality” is premised on the view that confidentiality, as “a one-on-one exchange between the healer and the patient”, rarely exists in traditional African culture.

A practical illustration of such shared confidentiality is found in Botswana’s National Policy on HIV. It proposes “shared confidentiality” as an ideal, but stresses that consent should be obtained from the HIV-positive person before the information is divulged. Ideally, “those who need to know” in order to provide appropriate health and social assistance should be told about a person’s HIV status. This policy departs from the premise that the individual is inextricably linked to a family and a community. The family is, therefore, encouraged to be involved from the pre-testing phase, as support structure, and not as a potential threat. According to this vision, HIV or AIDS is regarded not as “a matter of placing blame but of drawing together to cure”.

A more extreme form of “shared confidentiality” has found its way into the Botswana Medical Council (Professional Conduct) Regulations 1988, which allow medical doctors to “share” confidential information about the HIV status of patients. The amended regulations provide that “a person taking care of, living with or otherwise coming into regular close contact with the patient shall be informed about such patient’s medical condition” should that patient be HIV positive. By discarding the requirement of the patient’s consent, the notion of shared confidentiality has been extended. The broad category of people to whom the information may be disclosed (even including those with whom the patient has “regular

1 Ch 1 above; see also Zuberi, F (2004) HIV/AIDS stigma and human rights: A localised investigation of Hammanskraal communities (A report of the Tswelopele Project of the Centre for the Study of AIDS, University of Pretoria).
2 Female nurse in Focus Group (FG) 7 (Jubilee Hospital nurses).
4 Case v Minister of Safety and Security 1996 617 SA 165 (CC), per Didcott J (para 91).
5 Case v Minister of Safety and Security cited above.
6 National Coalition for Gay and Lesbian Equality v Minister of Justice 1999 (1) SA 6 (CC), eg para 23.
7 See www.3.who.int/whosis/factsheets, Fact Sheet 1.
10 After amendment in 1999.
close contact”) and the fact that none of them is under an obligation to keep the information confidential, lead Zuyderduin and Melville to conclude that these regulations are unconstitutional.\(^ {12}\)

Also the African Union’s major normative framework dealing with the rights of women, the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (the Protocol), invokes notions of shared confidentiality.\(^ {13}\) Under the heading “Health and reproductive rights”, state parties are required to ensure that their legal system provides for the right “to be informed on one’s health status and on the health status of one’s partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognised standards and best practices”.\(^ {14}\)

Set against this background, the monograph analyses and categorises the responses of interviewees relating to privacy, confidentiality and disclosure. It discusses a few reasons for, and consequences of, stigma attached to HIV status. The legal consequences and possible avenues of redress with respect to the identified types of disclosure are considered. Following this, the monograph deals with the question whether there is any duty for spouses (and sexual partners) or for health care workers to disclose the status of an HIV-positive person. Finally, the effect of the death of an HIV-positive person on the confidentiality of information is considered.

### 2. Forms of Disclosure

Five forms of disclosure are identified from the interviews: voluntary disclosure, non-professional breach of trust, lawful disclosure by health care workers, breach of professional duty by health care workers, and circumstantial inferences. Each of these is discussed below with reference to the interviews.

#### 2.1 Voluntary disclosure

A very small percentage of those estimated to be HIV positive are actually aware of their status. Few health professionals, even, have themselves tested and fewer ever disclose their results. Of the few that do get tested, even fewer disclose their status.

A reticence to disclose one’s status is directly linked to stigma: “If there was no stigma against people who are HIV positive people would easily disclose their status”.\(^ {15}\) A number of factors determine whether people who know that they are HIV positive disclose their status. One factor is the cleansing effect of disclosure: For some, the secret is too big to “keep to yourself and it eats you”; one needs to “confess” to a person one can trust and who will provide comfort.\(^ {16}\) Since he disclosed his status, said another, “I got healed”.\(^ {17}\) Disclosure also brings “peace of mind”.\(^ {18}\) Another factor that has been identified is the element of self-effacement. One male person living with HIV/AIDS (PLHA) thought that those who disclose are prepared to “swallow” their “pride”.\(^ {19}\) “Others cannot disclose because of pride, one feels that if I disclose I will lose my pride and people will not respect me like before, you see.” The difference between those who disclose, and those who do not, is pride: “pride kills so many people because they can’t cope because of pride”.

There are indications that an HIV-positive person first needs to deal with and overcome depression before facing the fact of seropositivity and disclosing his or her status. Another factor that increases the likelihood of disclosure is a supportive and nurturing family environment, although this is by no means a prerequisite.

---

\(^ {12}\) Ibid.

\(^ {13}\) Adopted in July 2003, in Maputo, Mozambique; the Protocol requires 15 ratifications to endure its entry into force; by 31 March 2005, 10 states had done so (see www.africa-union.org).

\(^ {14}\) Art 14(1)(e) of the Protocol.

\(^ {15}\) Thabo, FG12 (Moretele Youth Centre, youth group).

\(^ {16}\) FG13 (Tshwane Youth Development), Male 3.

\(^ {17}\) F2 in FG 1 (Moretele Sunrise Hospice – PLHAs).

\(^ {18}\) M4 in FG 1 (Moretele Sunrise Hospice – PLHAs).

\(^ {19}\) M3 in FG1 (Moretele Sunrise Hospice – PLHAs).
Some interviewees disclosed their status despite their family’s wishes, such as the instance of a woman whose mother wanted her not to disclose, but who went ahead because she wanted people to see her, as she thought she was going to die.20 Others were inspired by religious fervour to disclose.

Most importantly, disclosure shadows the progress of the disease: Many who disclose eventually do so only when they display clear symptoms of illness or when they experience a feeling of dependence, necessitated by need for care and treatment and, increasingly, access to medication. Even at this stage, people with access to private health care and antiretroviral treatment (ART), or highly active antiretroviral treatment (HAART), are less likely to disclose their status, and will avoid doing so due to a fear of the way their colleagues will treat them.21

The “voluntary” nature of the disclosure is relative—particularly with regard to limited disclosure. It may be the result of a confrontation, and may thus be a despairing effort to challenge stigma, as was the case with F3 (in Focus Group 3), who confronted her uncle’s derogatory comments at a funeral with the question as to what he would do if one of the members of his family were infected, in the process revealing her own HIV-positive status.

### 2.2 Non-professional breach of trust

If the HIV-positive person discloses publicly, or to a select group of people without any expectation or guarantee of confidentiality, he or she waives the right to privacy in respect of that information. The situation is however different where the person had entrusted the information to a specific third party, with a request or promise from that person not to divulge that information. Sometimes the trustee of such information adheres to the request,25 even if only out of self-interest, for example when an intimate family member, such as a mother, does not disclose further for fear of stigma that may be attached to her, or out of fear of what people will say.26

However, experience shows that this is no guarantee of this type of confidentiality. Some HIV-positive persons are afraid to tell even their best friends, because they fear headed sensationalism”, see Cameron, E (2005) Witness to AIDS 59-64.

20 Female 1 in FG5 (Clinical supervisors).
21 Interview KI12 (Community Liaison Officer, provincial Department of Social Welfare).
22 South African High Court judge Edwin Cameron disclosed his HIV-positive status in 1999 when he appeared before the Judicial Service Commission for a position as judge of the South African Constitutional Court. On his anguish about disclosing, and avoiding the risk of “wrong-headed sensationalism”, see Cameron, E (2005) Witness to AIDS 59-64.
23 Eg F3 in FG5 (Clinical supervisors).
24 KI16, interview with lay preacher at Elim Tabernacle Church.
25 F3 in FG1 (Moretele Sunrise Hospice – PLHAS) (“That girl did not tell anyone that I’m positive until today. It’s our secret. I got spiritually healed until today.”).
26 F3 in FG5 (clinical supervisors).
that these friends may tell someone else. One person reported that someone to whom she had entrusted the information subsequently referred to her as “Miss AIDS” in the presence of “so many people”.

2.3 Lawful disclosure by health care workers

The Medical and Dental Professions Board of the Health Professions Council of South Africa has issued a set of professional guidelines, entitled ‘Management of patients with HIV infection or AIDS’, in which it regulates the disclosure of HIV status.29 Departing from the position that “the results of HIV-positive patients should be treated at the highest possible level of confidentiality”, the guidelines state that a decision to “divulge” that information “must” be taken in consultation with the patient. If the patient’s consent cannot be obtained, the ethical guidelines recommend that the health care worker uses “his or her discretion whether or not to divulge the information to other parties involved who are at clear risk or danger”. The guidelines add: “To date, we have not had legal clarity regarding whether this situation is an acceptable limitation of the right to confidentiality.” The following steps are recommended:30

1. Counselling the patient on the importance of disclosing to his or her sexual partner and for taking other measures to prevent HIV transmission.
2. Providing support to the patient to make this disclosure.
3. Where the patient still refuses to disclose his or her HIV status or refuse to consider other measures to prevent infection, counselling the patient on the health care workers’ ethical obligation to disclose such information and requesting consent to do so.
4. Disclosing such information.
5. When informing the patient about the importance of disclosure, the attention of the patient should be drawn to the possibility of violence and other adverse consequences that such disclosure may hold in store for the patient concerned.

There are very few instances or references in the interviews to health care workers who, acting in terms of these guidelines, disclosed to a spouse, a sexual partner or care-givers of HIV-positive persons. A possible example is that of nurses at Jubilee who disclose to “grannies”, so that they know how to “handle” the children in their care. However, their view that they breach confidentiality and the omission of any reference to the “five steps” mentioned above seem to indicate strongly that their actions are not in terms of the guidelines. It is unclear from the study whether doctors are more likely to act in terms of the guidelines. Nurses have expressed deference to doctors in such delicate situations. In Jubilee Hospital, nurses “refer the person to the doctor because they do not want to divulge the status”.

2.4 Breach of professional duty by health care worker

Health care workers are alleged to disclose HIV test results outside of the framework of the guidelines, for instance to the “wrong people or friends”.33 “Some nurses do not understand the issue of confidentiality – they disclose to other nurses and this results in people not coming for tests”.34 The source of such information is the doctor/health care worker-patient relationship, and thus constitutes a breach of the medical guidelines.

27 F3 in FG3 (PLHAs).
28 F1 in FG2 (Moretele Sunrise Hospice – PLHAS).
30 The moral codes of the South African health profession are more or less in line with legislation adopted by some federal states of the USA.
31 F in FG7 (Jubilee Hospital nurses).
32 Female nurse in FG7 (Jubilee Hospital nurses).
33 F2 in FG1 (PLHAS – Moretele Sunrise Hospice).
34 KI13 (District health promotion officer).
and medical ethics. In the view of some, care-givers discuss the “condition more openly with outsiders than with the sick person” – especially some nurses.35

Disclosure may also be made indirectly, as the result of a code on the patient’s file, such as the code “279” used to indicate HIV infection, displayed openly to others,36 or through visits to HIV-positive persons who have not disclosed to their parents. An unexpected visit of health care workers may be perceived as a breach of confidentiality, when the mother sitting in the next room questions her child about the unexpected visit.

Confronted with the case of a domestic worker who is taken for an HIV test by her employer without her informed consent, and whose test results are revealed to the employer, most interviewees expressed a realisation that that would be wrong. A typical response is that the doctor should have asked the worker first if she “had an agreement with her employer about her blood tests”.37 Most agreed that “It’s up to you whether you tell your employers that you are HIV positive”.38

Often, health care workers (including social workers) reveal the status of HIV-positive patients out of frustration that the patient would not or does not disclose.39 One doctor ascribes this state of affairs to the less than ideal conditions prevailing in clinics, and explained that “… to expect health personnel to always react perfectly is unrealistic and if you add to that the traumatic increase and the burden that is put on to the clinic and the fact [of how limited] the resources are …”.40

2.5 Circumstantial inferences

‘Disclosure’ of HIV status may result not from a communication by someone with privileged information, but may rather be derived from circumstances. Most obviously, these circumstances may be AIDS-related symptoms, such as hair loss, weight loss, coughing, vomiting or diarrhoea. Such a deduction may be made by laypeople, based on correct or incorrect data, or may be derived from a more authoritative source, such as a doctor at a funeral who told of his suspicion of a person with swollen gums as being HIV positive because she showed the same symptoms as the deceased (who had died of AIDS).41

Inferences may be based on a person’s life-style or derived from a person’s association and relationships with known HIV-positive persons: “… once a person was living carelessly you find that once he or she fell sick people jump to conclusion that the person might be suffering from AIDS”;42 and, “Because you were involved with a suspected HIV carrier the community concludes that you are also infected.”43 In similar vein, going to an AIDS clinic immediately raises suspicion that someone is HIV positive.44 Even applying for social grants may lead to such inferences.

3. Consequences of and Reasons for (Non-)disclosure

On the one hand, stigma about HIV/AIDS is a consequence of disclosure, and fear of stigma is one of the main reasons for non-disclosure. On the other hand, non-disclosure itself is identified as one of the causes of stigma.

3.1 Non-disclosure induced by stigma

HIV-positive people often do not disclose their status for fear of stigma, which manifests itself in many forms.

35 KI13 (District health promotion officer).
36 F2 in FG4 (PLHAs).
37 F4 in FG3.
38 See eg F2 in FG3.
39 F2 in FG5.
40 KI15 (clinical doctor, working in area of Hammanskraal).
41 F2 in FG1 (PLHAs at Moretele Sunrise Hospice).
42 Interview FG11 (Moretele Youth Centre).
43 Keamogotswe in FG11 (Moretele Youth Centre).
44 Thabo in FG12 (Moretele Youth Centre).
Importantly, stigma is intertwined with, and often leads to discrimination. Discrimination is linked to the “othering” of those with HIV/AIDS. People believe it cannot happen to them, or they fear that it might. Discrimination is “something that prevents people from disclosing their status”, in that people treat HIV-positive persons differently, for example by not sitting next to them, or by refusing to drink from the same cup. Fear and avoidance of discrimination end in isolation, with the person staying at home, thus completely retreating from society. Much of this discrimination is the result of the conflation of HIV with AIDS. One reinforces the other – the “victim” is discriminated against because she does not disclose. A teacher who disclosed her status at work encountered stigma when fellow teachers scolded her; the year after her disclosure was considered the “worst, worst, worst” year in her life.

Disclosing one’s HIV status associates one with death, promiscuous sex, bewitchment and sin. Such stigma is exacerbated in particular by the association of AIDS with the triad of sex, death and the supernatural – all taboo topics in traditional societies.

Disclosure is tantamount to saying: I am contaminated with death, am about to die, even if death may be far off, and even if I am on treatment and AIDS could be rendered a chronic and manageable disease. Despite the advent of ARV treatment, the belief is still that an HIV positive status is equated to a death sentence. Living with HIV is considered as being in “a waiting room for death”. Those who manifest AIDS symptoms are dehumanised and are seen as the living dead, for whom there is “nothing left”, what they are “left with is death”. The fear of impending death perhaps explains the cruel neglect of the basic needs of those with AIDS symptoms, although such an attitude may be caused also by mere self-preservation, coping strategy for survival in a dire situation: “The friend will abandon you because they do not have time to wait and wash you...” Insufficient appreciation of the difference between HIV and AIDS, and of access to treatment increases stereotyping. This is illustrated by the experience of disbelief in reaction to disclosure encountered by some HIV-positive persons who appeared healthy: “I was not really discriminated [against] because people did not believe what I was saying ... So when they see a person who is HIV positive they think this person has no virus because ... they have to see the symptoms”.

Disclosure is tantamount to saying: I had illicit sex, sex in exchange for money, sex outside marriage, excessively or promiscuously. The perception exists that the disease is contracted through behaviour that is “questionable”, as if one “went all out to contract the disease”. By the time someone discovers that he is HIV positive, he would have had sex with a number of partners, making him afraid of revealing his status to previous and future partners. A prominent aspect of his being, his sexuality, is thus laden with guilt. “The day he discloses he will disclose having infected so many people.” This revelation will have a devastating impact on him as sexual being: retrospectively, all his partners will hold him accountable, prospectively, his sexual life is constrained, at the very least.

At first glance it is difficult to understand prejudice arising from the link between sex and HIV. Interviewees sketched a picture of a community in which many young children are sexually active, in which transactional sex is rife and in which promiscuity is not exceptional. Is it then not a supreme form of bigotry to visit those who contract

---

45 FG14 (Police Hammanskraal), Female 3; M3 in FG1 (Moretele Sunrise Hospice, PLHAS) (people are scared of AIDS and therefore do not want to associate themselves with it).
46 M1 in FG 1 (Moretele Sunrise Hospice – PLHAS) (people believe that if you are HIV positive you have to be very ill).
47 Disclosure may also be tantamount to saying: I am punished by God, for having sinned (F6 in FG 3 (PLHAS).
48 KI23 (Teacher).
49 F1 in FG1 (PLHAS, Moretele Sunrise Hospice)
50 FG11 (youth group, Moretele Youth Centre, Keamogetswe).
51 FG1 (PLHAS, Moretele Sunrise Hospice), Male 1.
52 KI21 (social worker).
53 F2 in FG1 (PLHAS, Moretele Sunrise Hospice).
HIV with stigma on the basis of these actions? This can perhaps be explained by the human tendency to identify scape-goats who carry the blame and fear of us all, or by a tendency of ‘othering’ those who pose a risk to us. From another angle, this form of stigma may be viewed as the contradictory impulse of a society that is at war with itself, a war between tradition and modernisation, where traditional sexual mores have broken down, and are no longer to be relied upon, but function as a deep-seated frame of reference when moral judgement calls are made.  

HIV’s perceived link to death is complicated further by the link of HIV to sexual promiscuity. Sex, a taboo subject, becomes inscribed on the face of the individual, and of society. HIV infection is thus regarded as the result of sex-that-leads-to-death.

Disclosure is tantamount to saying: I am bewitched. Against death and witchcraft, which is linked to the “supernatural”, everyone is powerless. HIV/AIDS stigma is thus reinforced by feelings of powerlessness and the refusal of individual responsibility in caring for the HIV-positive or AIDS-symptomatic person in the face of the magnitude of these forces.

The inevitability of death and the overwhelming burden of stigma perhaps explain the suicide narrative underlying many of the interviews, for example the account of a girlfriend who committed suicide after her boyfriend died and she was thought HIV positive. A teacher who disclosed her status, first to her family and then at work, comments as follows: “If I was not strong I think I could have committed suicide because you know at school in a staff room … [someone would] even bring along condoms to show that people who are HIV positive must … use such things …”.

Disclosure is a gendered affair. Women, who access health care services more regularly than men, especially when they are pregnant, are thus more likely to be tested for HIV, and to be faced with the choice whether to disclose. This situation has given rise to the stigmatisation of the partner who discloses first, without regard to the circumstances of the disclosing partner’s seroconversion. Any discussion about the possibility that the non-disclosing (usually male) partner may have infected the disclosing partner is impossible due to the assumption that the party who disclosed first is to blame for bringing HIV into the home or relationship.

Women are therefore reluctant to disclose to their male partners because they fear blame, rejection and violence. After rejecting his female partner, the male partner is likely to explore new sexual relationships without mentioning the possibility of being infected. He will deny that he is HIV positive or that he is involved in the infection; he will end the relationship, and he will “be having sex with another woman without telling her that [his] previous partner said this and that, he will just keep quiet”. A rudimentary cost-benefit analysis shows significant adverse consequences (to the woman) and very little benefit (to either the woman or society). Her disclosure will end the relationship, but will not prevent the spread of HIV.

### 3.2 Stigma induced by non-disclosure

A number of interviewees insisted that the lack of openness and disclosure feeds stigma. The lack of disclosure causes the disease to be revealed only at its end-stage, as full-blown AIDS, when there is nowhere left to hide, when, in the shadow of impending death, the body makes disclosure irrelevant. In this way one of the underlying roots of HIV/AIDS stigma is reinforced, namely, its close association with physical decline and inevitable death.

---

54 As one interviewee put it, people are afraid of “many new things” (interview FG 11).
55 Clinical doctor working in the area of Hammanskraal (KI15).
56 Michael in FG11 (Youth group, Moretele Youth Centre).
57 F2 in FG1.
58 F2, F3 in FG1.
59 F2 in FG1 (Moretele Sunrise Hospice – PLHAs).
Also, non-disclosure gives rise to the image of the HIV-positive person as devious destroyer. Some interviewees remarked that it is due to secrecy that an HIV-positive person is isolated, and it is due to secrecy that rumours start spreading. When someone is “forced” to disclose after showing undeniable symptoms of illness, this may come in the wake of numerous infections, "like you killed many people." 

4. Laws Upholding the Right to Privacy

In general, members of the community feel that the police do not take complaints about breaches of confidentiality seriously. The police respond by either feigning helplessness (“What must we do?”) or by questioning the complainant’s version (“Do you really have it?”). The next part of the monograph investigates the extent to which the legal environment enables disclosure and provides remedies in respect of breaches of the right to privacy.

4.1 Voluntary disclosure

A person who waived his or her right to privacy cannot reverse that decision once the information is in the public domain. Disclosure depends less on the individual will and conscience of the HIV-positive person, and more on the nature of the immediate “public domain” into which the revelation has been made. The applicable legal framework plays an important role in either dissuading or encouraging disclosure.

Although the Constitution guarantees the right to privacy and the right to equality, it is silent about HIV and AIDS. Other laws, however, to some extent provide an enabling environment for disclosure. This is especially true in the employment sphere. The Employment Equity Act prohibits unfair discrimination on the basis of HIV, in effect allowing an employee to disclose his or her status free of fear for retaliation. Although HIV and AIDS are not included as specific grounds for non-discrimination in South African anti-discrimination legislation, the Constitutional Court’s decision in Hoffmann v SAA has gone a long way towards establishing HIV status as a ground analogous to those explicitly mentioned in the Constitution and the Promotion of Equality and Prevention of Unfair Discrimination Act.

In the Hoffmann case, the Constitutional Court refers to stigma: “Notwithstanding the availability of compelling medical evidence as to how this disease is transmitted, the prejudices and stereotypes against HIV-positive people still persist. In view of the prevailing prejudice against HIV-positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity. The impact of discrimination on HIV-positive people is devastating.” A number of cases have been brought to equality courts alleging discrimination on the ground of HIV status.

An enabling legal regime also needs to address factors that impede disclosure, such as gender inequalities making it impossible for women to disclose without the fear of unpunished domestic violence or loss of material security. An enabling environment depends on whether laws are enforced and on whether these laws become part of the reality of people’s lives. To achieve this, government has to make available sufficient resources for legal assistance, sex education, policing and the implementation and enforcement of strategies and efforts.

---

60 Nurse, FG6 (Jubilee Hospital nurses).
61 F2 in FG1.
62 F3 in FG4 (PHAS).
63 M1 in FG1.
64 F2 in FG1.
65 Sec 6(1) of the Employment Equity Act.
66 2001 (1) SA 1 (CC).
68 Para 29.
4.2 Breaches of trust

The HIV-positive person’s right to privacy entails a concomitant legal duty to respect that right on the part of anyone entrusted with confidential information. When someone to whom confidential information is entrusted discloses that information contrary to the wishes of the person who entrusted that information, both civil law and criminal law consequences may result.

Should the relationship of trust be based on an agreement between the HIV-positive person and the person who breaches the trust, disclosure constitutes an infringement of privacy and a breach of contract, and could lead to a delictual claim for damages.⁶⁹

Although the possibility of defamation is alive in the minds of interviewees, its application is not without complication. This is so particularly because one of the defences against a claim for defamation is the truth of an assertion that is in the public interest. As defences, the content of “truth and public interest” must be determined with reference to what is objectively reasonable. In other words, a person who is HIV positive will be unable to succeed with an action for defamation if such disclosure is shown to be in the public interest. Matters in the “public interest” refer to material “in which the public has an interest”, rather than material “which is interesting to the public”.⁷⁰

A special relationship of trust may exist between the party providing the information and the party breaching confidentiality. A doctor’s anguished decision to disclose to a sexual partner, after having followed the steps prescribed by the Guidelines, is very different from the “McGeary-type” disclosure.⁷¹ Before his death of AIDS, McGeary was a patient of Dr Kruger. McGeary went to his doctor for an HIV test, in order to qualify for life insurance. When Dr Kruger communicated his HIV-positive result, McGeary insisted that the information be kept confidential. Despite this request, and the doctor-patient relationship existing between McGeary and Dr Kruger, the doctor disclosed this information to two other individuals, who then told others. As is often the case with such sensitive details, gossip spread fast and wide. The Court described the two persons to whom Dr Kruger communicated the confidential information as “colleagues” – another general practitioner and a dentist. Even though the dentist in question on a previous occasion acted as McGeary’s dentist, there was no indication that McGeary was returning to that dentist. The other medical practitioner had no interest in the information. Also, the disclosure took place while the three men were playing golf.

The Court held that in this case the correct cause of action is the actio iniuriarum, as the claim was for sentimental damages. The Court rejected the doctor’s defences that the communication to his “two colleagues” was privileged, and objectively reasonable and in the public interest. In particular, Dr Kruger’s argument that McGeary may potentially have infected Dr Kruger was not given any serious consideration.⁷²

Rumours about someone’s HIV status may be spread by people who have received the information directly or indirectly through a breach of trust or of professional codes, or by people making their own inferences. No liability attached to this form of gossip. It is interesting to note that, in McGeary’s case, the appellant did not pursue the matter against the doctors’ spouses, who spread the news that they had received second-hand. The claim could conceivably have been brought against Dr Van Heerden (the other general practitioner), as well, since he “could not deny that Dr Kruger requested him” to treat the information in confidence.⁷³ Instead, the appellant directed himself to the initial “source” of the leak, Dr Kruger.

⁷⁰ National Media Ltd v Bogoshi 1998 (4) SA 1196 (SCA), para 25, per Hefer JA.
⁷¹ Jansen Van Vuuren v Kruger 1993 (4) SA 842 (A).
⁷² At 851I.
⁷³ At 851I-H.
In respect of Dr Van Heerden, his wife, and others, the question is: Is it wrongful for someone who had been told information confidentially to disclose such information? Neetling et al conclude that, in the absence of a specific agreement between the parties, such a disclosure is “harmless and in accordance with human nature”, even though the initial disclosure was intended for a specific person or persons only. “That people gossip about one another and repeat what they are told or see is a fact of life. Thus it would be contrary to legal convictions and reality to class each of these instances as an infringement of the right to privacy.”\(^\text{75}\)

A gossip mongerer who spreads a factually incorrect rumour that someone is HIV positive exposes himself to an action for damages. However, the wisdom of instituting such an action is debatable: Such an action departs from the premise that an HIV-positive status necessarily equals an insult or constitutes damage to that person’s reputation. While it may be true that the majority of South Africans view HIV status in a negative light, such decisions are likely to reinforce the stereotypes and stigma.\(^\text{76}\) At the same time, the insulting nature of an utterance depends on the context in which it is made: In 1950s South Africa, for example, a litigant’s claim for defamation succeeded on the ground of being called a “Communist”.\(^\text{77}\) Similarly, a claim for “HIV defamation” may be viewed as reflecting the stigmatised context within which the utterance has been made, without the person subscribing to that context.

Breaches of confidentiality also expose the person breaching confidentiality to criminal prosecution. Among some interviewees there is a conviction that “if you spread a rumour about someone else’s HIV status without his/her consent the law treats it as an offence”.\(^\text{78}\) The police have a role to play in “stopping those people from spreading the rumour about your HIV status”.\(^\text{79}\) Two crimes are potentially committed by the person: crimen \textit{iniuria} and criminal defamation. \textit{Crimen iniuria} is the unlawful, intentional and serious violation of the dignity or privacy of another, while criminal defamation is the unlawful and intentional publication of a matter concerning another person, which tends to injure the dignity of that person.\(^\text{80}\) Conceivably, criminal proceedings could also have been brought against the doctor, above, in the form of criminal defamation.

4.3 Conclusion

The law does not establish an unambiguous enabling environment for disclosure. Although there is a general awareness that breaches of confidentiality may give rise to legal remedies, practical problems such as a lack of access to legal advice or assistance, and a lack of serious attention by the SAPS, have rendered the impact of these legal possibilities negligible. Additionally, the law seems to have nothing to say about one of the main problems – community gossip. This state of affairs highlights the limits of what laws can accomplish, on the one hand, and the importance of dealing with stigma at the societal level and of devising communal strategies, on the other.

5. A Duty to Disclose?

5.1 Background

Few circumstances emphasise the societal embeddedness of the individual as well as the relationship between the HIV-positive person and his or her spouse or other sexual partner. On the one hand, the individual treasures privacy and may be reluctant to reveal his or her HIV status. Such reluctance is reinforced by the long-accepted principle of the sanctity of the doctor-patient relationship.

\(^{74}\) Neethling, J et al, note 69 above 249.
\(^{75}\) Jansen van Vuuren, note 71 above 249-250.
\(^{76}\) See Tothill v Foster 1925 TPD 857.
\(^{77}\) Sachs v Werkerspers Uitgewersmaatskappy Edm Bpk 1952 (2) SA 261 (W).
\(^{78}\) FG 11 (Moretele Youth Centre).
\(^{79}\) Ibid.
On the other hand, some argue that invoking this principle may have a negative effect, asking for its reconsideration in the light of the pandemic. Such reconsideration posits the individual’s right to privacy against the interests of society, thus reinforcing the perception that rights are overly individualistic and counter-communitarian, that rights undermine society and that they in fact “assist” those posing a threat to society. These concerns need to be taken seriously, and are addressed in the context of the question whether the state has a duty to ensure that the HIV-positive status of individuals is revealed to sexual partners. Put differently: Will the problems pertaining to stigma be resolved by placing an obligation on sexual partners and health care workers to tell?

In the view of some interviewees, confidentiality has been overplayed, and is regarded as having “caused much of the problem that we have”, “the sooner we get rid of confidentiality the better”.

There is also some who are of the opinion that the right to privacy protects those who are infected. Their solution would be to impose such an obligation. One person said children are “too involved with their ‘freedoms’ and there is no focus on their responsibilities”. A strong sentiment is that the right of people not to disclose their status has resulted in the spread of the disease. HIV/AIDS “needs to come in the open because it is ruining the country. It is not coming into the open because of human rights”. The view is also expressed that disclosure reduces anxiety.

In contrast, there are those who emphasise confidentiality: “There is no person who has a right to disclose the status of another person because it’s only a person who is HIV positive to reveal his status; you don’t have that right because you have to talk about your own status, not of another person”. They emphasise that stigma exists, and that a few disclosures are not going to undo that.

In fact, the forced outing of HIV-positive people exposes them to stigma, as those who were unwilling to disclose, as threats to society, and they will be branded with even greater stigma.

The following few pages of this monograph investigates how the countervailing forces or claims of confidentiality and disclosure are to be reconciled.

5.2 A duty on HIV-positive persons to disclose to care-givers?

One of the nurses at Jubilee Hospital felt that an HIV-positive person should “at least tell someone who is closer to them ... so those people who are taking care of them can protect themselves with gloves”.

The 1989 and 1992 version of the South African Health Professions Council’s Guidelines provided that, when a patient that had been counselled refuses to disclose his or her HIV status, “the doctor shall consider it a duty to seek to ensure that any sexual partner is informed in order to safeguard such a person from a possible fatal infection”. In 1993, the duty to inform was changed to a right to inform: “The health care worker clearly also ethically has the right to inform identifiable sexual partners of the HIV-positive status of a patient”. The 2001 version allows it to be in the health care worker’s discretion to determine “whether or not to divulge the information to other parties involved who are at clear risk or danger”.

Attempts have been made to spell out the duty to disclose in clear terms. In 1999, the then Minister of Health, Dr Nkozasana Dlamini Zuma, proposed regulations imposing an obligation on health care workers to disclose a patient’s AIDS condition (and not HIV status) to immediate family.

---

81 KI15, clinical doctor.
82 F2, FG4 (PHAS).
83 Interview KI13 (Community radio presenter).
84 Interview KI14, SANCO member, Hammanskraal.
85 Clinical doctor working in the area of Hammanskraal (KI 15).
86 Male PLHA, Moretele Sunrise Hospice FG1.
87 F in FG7 (Jubilee Hospital nurses).
members and health-care providers. According to the government publication *South Africa Yearbook 1999*, the "Cabinet has emphasised that this is not meant to, nor will it, breach citizens’ right to confidentiality and privacy".

Resistance against these proposals was two fold. First, the timing of the disclosure makes little sense. As this survey illustrates, voluntary disclosure becomes more likely as HIV progresses and inscribes itself more visibly in the form of AIDS on the body. However, as a person is most likely to infect others when he or she is healthy, asymptomatic, and some argue, consequently more sexually active, it is during this phase that disclosure should take place, if at all.

Secondly, the target audience of the proposed disclosure is misplaced. The interests of immediate family members or health care providers in this information are very limited. In so far as such disclosure may be justified, it should be aimed at sexual partners or others who present an immediately identifiable risk of infection. The notion that the family should be informed of a family member’s HIV status seems to derive from the view that in traditional African culture “matters of disease and death are seldom individual concerns, but affairs of the family or even the entire community”. However, confidentiality within a family is often maintained so as to avoid stigmatisation. The research here shows little indication of consistent disclosures to family members. It is certainly true that, for some with HIV (and particularly AIDS), “it is unthinkable not to have family ... closely involved”, but for many others the choice may be different.

### 5.3 A duty on health care workers to disclose HIV status to sexual partners and spouses?

At the outset, the content of the Guidelines should be clarified. It seems that they may be interpreted as either permitting but not requiring disclosure, or as entailing an obligation to disclose.

Although the Guidelines are worded to allow a discretion to permit partner notification, it may be argued that they in fact compel disclosure once the health care worker has identified a specific individual who is at a clear risk of HIV infection in the event of non-disclosure. At common law, a health care worker owes a duty of care not only to his or her own patients but also to other patients at large. A partner at risk may sue a doctor for failing to disclose information if the doctor exercised his or her discretion against disclosure and, as a result, the partner at risk becomes infected. In that sense, the discretion is very constrained, and effectively amounts to a duty as the exercise of the discretion not to disclose may give rise to legal liability. In practice, then, the discretion amounts to an obligation once the health care worker has determined that someone is at a clear risk of infection from the tested person.

The question as to what a doctor’s duty of care entails, is determined with reference to the standards of reasonableness as set out in the legal convictions of the community (*boni mores*). Will it be considered reasonable and in the community’s interest to disclose? Some guidance is found in the American case of *Tarasoff v Regents of the University of California*. Although this case does not deal with HIV, it is relevant to the question whether there is a duty to disclose the status of an HIV-positive person to someone under immediate threat of infection.

---

89 In terms of proposed regulations published in the Government Gazette No R 485 on 23 April 1999.
90 Available at www.lks2southafrica.com/Health.
92 Ibid.
93 Ibid.
94 551 P 2d 334 (Cal 1976).
In that case, a psychiatric patient told a psychologist of his intention to kill his girlfriend on her return to the campus. Despite believing that the patient posed an immediate threat to the woman, the psychologist did not disclose this information to either the woman or her family (he did, however, alert the university security). The patient's subsequent murder of the girlfriend resulted in a finding that the psychologist had a duty to notify the potential victim. It may be deduced from Tarasoff that health care workers have a duty to inform known and identifiable sexual or needle-sharing partners of an HIV-positive patient's infection if there are clear indications that the HIV-positive person will engage in activities exposing partners to an imminent risk of infection.

However, it may also be argued that the immediate and clear risk of death or harm in Tarasoff is distinguishable from the relatively remote possibility that the sexual partner of the tested person would be infected with HIV. In the absence of a comparable clear and immediate danger, a doctor's clear and overarching obligation to keep information confidential should override any duty of care to other patients.

Accepting that the Guidelines impose an unequivocal duty to disclose on health care workers, the question arises whether this position meets constitutional muster.

In any society where the Constitution represents the highest law, any answer has to anchor itself in that document and its value system. In terms of the South African Constitution, a two-step (or two-phased) approach to determining constitutional validity asks: Is there a prima facie violation of the applicant's rights? If so, can the measure occasioning this violation (the 'limitation') be justified under article 36 of the Constitution, as being reasonable in a democratic society?

In the discussion that follows, each of these elements is analysed. The situation of a person who has tested positive for HIV (the tested person) and who is in a relationship with a sexual partner is considered, although admittedly the problem may arise in other contexts as well, for example when drug users share needles.

5.4 Phase one of constitutional analysis: Prima facie violation

In so far as the Guidelines allow for an obligation to disclose a tested person's HIV status to a partner, the Guidelines arguably constitute a prima facie violation of the rights to privacy, to dignity, to “bodily and psychological integrity” and of the right to equality.

Routine disclosure of the HIV status of a member of a discordant couple constitutes a prima facie violation of the tested person's right to privacy in personal information. Section 14 of the Constitution should be interpreted to include the “protection from disclosure of information given or received by the individual confidentially”95 and should include a decision “when and under what conditions private facts may be made public”.96 Information about an HIV diagnosis is evidently of great importance to the individual, and is closely linked to the most intimate sphere of the human personality.97 Particularly in a society where HIV is burdened with stigma, tested persons will treasure their autonomy in any decision to disclose this information to third parties.98 Disclosure strikes at the heart of the healthy HIV-positive person. In a society where HIV equals contamination in the eyes of the majority, knowledge of HIV status contaminates perceptions and relationships – not only by revealing the “diseased” body's physical condition and calling into question the other's ability to live with it, but also by inscribing onto the body past...

---


96 National Media v Jooste 1996 (3) SA 262 (A) at 271.

97 The European Court of Human Rights found a disclosure of “information of a private and sensitive nature” to interfere with the right to respect for private life in art 8(1) of the European Convention: MS v Sweden (1999) 28 EHRR 313, para 41.

98 See eg Harris v Trigg 941 F 2d 1495, 1514 (11 Cir 1991).
actions and practices, perhaps even introducing into the relationship previously undisclosed knowledge.

A breach of the right to privacy need not constitute a breach of the right to dignity, but often does, as is the case here, as disclosure would lead to the publication of information that is at the very least embarrassing, and at worst life-threatening to the tested person. Varying degrees of impaired dignity naturally lie between these two extremes.

The right to freedom and security of the person also comes into play. There are numerous examples in the interviews of serious neglect of people whose HIV status has been disclosed. Women, in particular, may be exposed to domestic violence from their sexual partners or spouses.

Even if a duty to disclose gender is neutral on its face, its application will affect women disproportionately, due to the gendered nature of stigma. Women are more likely to access health care services and are, therefore, more likely to be tested for HIV. As a result, women can become victims of the presumption that the first person to disclose their HIV status is the originator of the virus in the relationship. At the same time, women — especially rural women — are seriously constrained in their ability to negotiate safe sex practices. Women are also biologically more susceptible to infection. In fact, it is estimated that 3.1 million women, compared to 2.4 million men, were infected with HIV by the end of 2003. A duty to disclose therefore constitutes indirect discrimination on the grounds of sex and gender.

### 5.5 Phase two formal constitutional analysis: “Law” of “general application”?

Restrictions on rights are only justifiable if they qualify as “law of general application”. Do these Guidelines constitute “law”? It has been suggested that a measure must conform with the requirements of adequate accessibility, sufficient precision in its formulation and non-arbitrariness in order to qualify as “law”. Another aspect may relate to its democratic legitimation. Democratic legitimation encompasses both the source and the process of legitimation (or formation or adoption). The rationale for only allowing “law” to justify limitation partly lies in the doctrine of the *trias politica* — in terms of separated powers, only the legislative branch may limit rights. The executive may apply these laws, and, acting under their authority, justifiably limit rights. In terms of the process of its adoption, to qualify as “law” a norm or rule has to be adopted as a result of a deliberative and public process to which nationals have access, on which they may bring some influence to bear, and where the law is capable of being corrected. Legislation clearly conforms to this criterion, but so does court-made common law, as it is developed in public fora, through deliberation to which the public has access, and that may be “corrected” through appeal and argument.

Clearly, legislation, delegated legislation, rules of the common law developed by courts and customary law rules meet these criteria. But what about guidelines issued by statutory bodies, such as by the Health Professions Council of South Africa? Authors have expressed some uncertainty as to whether they constitute “law”. It is thus possible that the quest for justification may fail at this very first hurdle.

---

99 Sec 12(1)(c) of the Constitution.
101 Sec 9(3) of the Constitution.
102 Sec 36(1) of the Constitution.
103 See eg President of RSA v Hugo para 102 – 104. See also the European Court of Human Rights, Andersson v Sweden (1992) 14 ECHR 615, para 90: the term "in accordance with law" (in eg art 8(2) of the European Convention) refers "primarily to domestic law .... These requirements relate to the quality of the law and can be summarised under the headings ‘accessibility’ and ‘foreseeability’".
In the present case, the following factors need to be taken into account: The Guidelines were issued by a body established in terms of statute, the Heath Professions Council of South Africa. The issuing of guidelines falls within its competence. The Guidelines were not published in the Government Gazette. The guidelines are communicated in each particular case to the person concerned, allowing him to direct his actions accordingly. The discretion allowed to health care workers is very wide, and does not seem to have led to a consistent practice. The European Court of Human Rights has observed that a “law which confers a discretion on the authorities must indicate the scope and manner of exercise of any such discretion with sufficient clarity to afford the necessary protection”.  

There may be a problem with the accessibility of the Guidelines, in the sense of enabling the person affected to regulate his conduct, plan what steps to take, and not to be “surprised”. The issue is: the whole train of events described above will mostly be set in motion when a person voluntarily has himself tested, and then finds that disclosure follows. The fact that the rules are explained to him once he is tested does not remedy the defect in his initial knowledge, which may have had a dramatic impact on his decision to undergo the test in the first place.

However, an overly facile dismissal of the “legal” status of such guidelines may have negative consequences. A court interpreting a right (in phase one of the analysis) may take into account the impossibility of justifying grounds (in phase two) and thus interpret the right restrictively, as part of the phase one inquiry. For this reason, it is argued here that “law” should not be interpreted too restrictively, allowing measures to be evaluated for substantive compliance with section 36 if they meet the minimum requirements of “law”.

5.6 Phase two substantive constitutional analysis: A reasonable and justifiable limitation?

Once it has been established that a limitation (such as that part of the Guidelines allowing a doctor to disclose the HIV status of a patient to a sexual partner) constitutes “law of general application”, the party relying on the limitation has to persuade the court that the limitation is also “reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom”. This process requires a weighing up of the nature of the right, and the extent of its limitation against the importance of the purpose of the limitation, as well as the relation between the limitation and its purpose. The answer to the question whether there are less restrictive ways of achieving the purpose of the limitation also enters into the equation.

Nature of the right

Disclosure of a person’s HIV status strikes at the core of individual autonomy in that it forecloses the ability of that person to decide how and to whom intimate personal data or information should be communicated. The personal information over which the individual loses control is central to the sphere of his or her personal life, and has a bearing on both the past and the future.

Arguably, the right most clearly at risk is the right to privacy. As a classic “first generation right”, the right to privacy has evoked the criticism that it may place the individual in a cocoon, insulating singular interests from their inevitable embeddedness in society. It has been argued that this view of privacy has caused this right to be omitted from the African Charter on Human and Peoples’ Rights. In its interpretation of the right to privacy, the South African Constitutional Court displays a con-

105 Andersson v Sweden (1992) 14 ERR 615, para 90.
106 Sec 36 of the Constitution.
sciousness of these criticisms. In *Bernstein v Bester*\textsuperscript{107} Ackermann J holds that “rights, like the right to privacy, are not based on a notion of the unencumbered self, but on the notion of what is necessary to have one’s autonomous identity ... In the context of privacy this means that it is ... the inner sanctum of the person such as his/her family life ...”.\textsuperscript{108} When the ‘truly personal’ becomes entangled in the web of “communal relations and activities”, the result is that ”the scope of personal space shrinks accordingly”.\textsuperscript{109} Finding sodomy in violation of the right to privacy in *National Coalition for Gay and Lesbian Equality v Minister of Justice and other*, he summarises his view in the *Bernstein* case that “rights should not be construed absolutely or individualistically in ways which denied that all individuals are members of a broader community and are defined in significant ways by that membership”.\textsuperscript{110} In a similar vein, and in the same case, Sachs J remarks that the “Constitution does not presuppose that a holder of rights is an isolated, lonely and abstract figure possessing a disembodied and socially disconnected self. It acknowledges that people live in their bodies, their communities, their cultures, their places and their times”.\textsuperscript{111}

Through a construction of a public/private divide, a sliding scale of privacy is suggested. In the inner sanctum of the truly personal, maximum privacy may be claimed. As individuals interact increasingly in the public realm, they increasingly sacrifice or forfeit their privacy claims. Such a construction tends to regard the “home” as a harmonious non-conflictual space.\textsuperscript{112} As AIDS often shows, far from being an inner sanctum in which privacy is treasured, the family sphere becomes the very site in which privacy is challenged.

The case law seems to suggest an interpretation of privacy embedded in the community. Privacy should not serve as a fiction to undo the reality of the relationships in which the individual engages. Put differently, the right is important, but its invocation should not serve as a vehicle to deny or undo an individual’s inextricable or inherent or specific relationship with other individuals, groups or the community.

**The purpose of a legal duty to disclose, and its importance**

The rationale for imposing a duty to disclose (explicitly or by implication) differs with respect to an uninfected and an infected partner.

Disclosure is aimed primarily at preventing the seroconversion of an uninfected partner. The assumption is that, given the prejudice against and fear of HIV, partners in a sexual relationship are likely to reduce exposure to HIV by changing their sexual practices or their partners.

Disclosure is aimed also at ensuring access to medication to the partner who has been infected. Very few people are aware of their status, making early medical intervention unlikely. This is particularly pertinent in the case of a pregnancy, where the mother may take steps to establish her status and direct her pregnancy accordingly.

Cumulatively, these two specific objectives are aimed at ”saving lives”.

These objectives carry much weight in South African society. According to the most reliable source of HIV infection in South Africa, the 2003 National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa, 27,9% of pregnant women attending clinics are HIV positive.\textsuperscript{113} This marks a continuation of a relentless escalation, increasing from 0,7% in 1990, to 24,5% in 2000, and up from 26,5% in 2002. Extrapolated to the

\textsuperscript{107} 1996 (4) BCLR 449 (CC); 1996 (2) SA 751 (CC).
\textsuperscript{108} Para 65 and 67.
\textsuperscript{109} Para 67.
\textsuperscript{110} National Coalition for Gay and Lesbian Equality v Minister of Justice note 6 above para 31.
\textsuperscript{111} Para 117.
\textsuperscript{112} Mistry v Interim National Medical and Dental Council of South Africa 1998 (4) SA 1127 (CC) para 27.
wider society, the Survey concludes that an estimated 5.6 million South Africans are HIV positive.

These objectives serve to support rights that may be seen to be in conflict with the right to privacy (and dignity). The following observation should be kept in mind: “The truism that no right is to be considered absolute implies that from the outset of interpretation each right is always already limited by every other right accruing to another citizen.” 114 These countervailing rights are the right to life, the right to bodily integrity, including the right to “control over” one’s body, access to health care, all of which the state must guarantee.

A third goal may also be introduced, that of the care of the individual. It is arguably better that those close to the infected person know, so that they could provide support, so that they would have an understanding of what the person goes through, and be able to ensure good nutrition, and medication. If the person’s immediate family does not know, it is unlikely that he will feel free to acquire access to medication, avail himself of possibilities of access to medication, and conform to the rigorous regime of compliance.

Although the information should, in terms of amended Guidelines, be provided to the sexual partner alone, there is no impediment on the informed partner to pass the information to others. This goal would in fact assume that the informed partner would tell at least other immediate family members or close friends. The communal interest comes to the fore more than in other respects. The group challenges the right of the individual to maintain a monopoly on the information, invoking the need of other members of society to share in the burden, for the benefit of the infected individual. Such an approach brings autonomy and paternalism in conflict. A coercive inroad into autonomy can only be justified in order to prevent harm to others, but to prevent harm to self. It may also lead to the community imposing censure on the individual, not restricting his life choice in his own interests.

**The nature and extent of the duty to disclosure, and its impact on rights**

For notification to be undertaken, there needs to be a uniquely identifiable individual, not a category of persons. At first glance, then, the limitation seems limited in its scope and effect, as the disclosure is aimed at a specified and uniquely identifiable individual. However, the problem is that there is no guarantee or even effort to curb further diffusion of the information, allowing the possibility of a breach of trust to turn into limitless gossip.

In order to interpret the nature and extent of the disclosure, the process in terms of which disclosure takes place should be analysed. Working on the assumption that the tested person is at present involved in a relationship, the health care worker has to engage in a dialogue, or question-and-answer-session, with the tested person.

First of all, it must be established if a substantial risk of infecting the sexual partner of the tested person exists. Put simply, the health care worker should ask whether the partners engage in unprotected penetrative sexual intercourse, and are likely to continue doing so. The question arises whether the concern here relates to the future, emphasising prevention, or whether it concerns the past. In the USA, the law of the state Alabama for example allows notification if there is a “forseeable, real or probable risk of transmission”, 115 seemingly focusing on both potential present and future exposure. In South Africa, the HPC Guidelines talk of parties “who are at clear risk of danger”. Being at risk seems to lie in the present and future, in prevention of further and future

114 Ackermann, J in Bernstein note 107 above para 67.
risk. Such an interpretation implies that there is no clear risk of danger or transmission if the tested person pledges to have only protected or “safe” sex in the future. It may be questioned whether this is a satisfactory solution. The test reveals that past partners could have been exposed and that past sex with the present partner could have posed a risk of transmission. Should the inquiry about risk be extended to include past partners and past conduct, or should it only concern future conduct? It seems clear that the retroactive application of the information is very dubious, as the status of the tested person is determined only then. The assumption should be that it is too difficult (if not impossible) to establish when exactly the tested person sero-converted.

Success in this process of establishing risk relies on a combination of confession and cross-examination on the part of the health care worker. The model scenario assumes rational actors, and truthfulness from the tested person. Exercising their discretion or reaching a “belief” cannot rely entirely on the version of the tested, or a contradictory intuition on the part of the health care workers. It is clear that the law imposes its own discourse onto health care workers, as they are in essence required to establish what is “reasonable” or “clear” through cross-examination. If this is not what is required, health care workers would have to rely on the mere say-so of the tested person. However, it is questionable whether health care workers have the skills and time to perform these functions, and whether clinics are appropriate venues for such sessions.

If a clear danger or significant risk to an identified partner is established, the health care worker should move into counselling mode, informing the tested person of the risk of transmission arising from a continued unprotected sexual relationship with the identified partner. By this stage, the tested person would have realised that he needs to tell the partner, so that the partner can have herself tested, decide whether to end the relationship, or to change the nature of sexual intercourse. An already reluctant person would by now be even less likely to disclose, as he realises that disclosure is likely to signal an end of the current state of the relationship.

Once the health care worker feels satisfied that the message has reached its immediate audience, it must be established whether the person will actually reveal the information to the partner at risk. Even if the counselled person had been honest and forthcoming up to this point, he may now have misgivings about being honest about exposing the partner to risk. The easiest would be to acquiesce, agreeing to disclose, but without a true intention to do so. Alternatively, the tested person may say that he will not tell the partner, but will refrain from engaging in unprotected sex, in the light of the information provided during the counselling. This means that the process returns to its beginning, as there is no longer any clear risk to the partner, and the matter ends. Again, the health care worker is entirely reliant on the tested person’s responses to questions.

If the tested person should fail to volunteer to change conduct or to inform the partner voluntarily, the confrontational phase starts. The health care worker needs to threaten the person that she will reveal the status to the partner if he does not do so himself. The HIV-positive person now has a last opportunity to accept disclosure.

This leads to questions as to how this will happen in practice. The health care worker relies on the tested person for information, such as the partner’s name, telephone number and address. It is not conceivable that health care workers are able to visit all partners at risk. They will most likely make telephone calls inviting partners to come for a consultation. The information cannot be given by phone, and needs to be preceded by counselling to the partner. By this time, it is quite possible that the partner will already suspect the true state of affairs, and may decide to deal with the matter immediately or not to go for the consultation at all. There is no guarantee how the partner will react under these circumstances, or even after receiving counselling. In a society of deep-seated stigma and prejudice he may
react violently. The Guidelines do not sufficiently take into account this possibility.

**Relation between the disclosure and the purpose of “saving lives”**

Some have glibly commented that the debate about disclosure presents a choice between the right to privacy of the infected person and the right to life of the sexual partner.\(^{116}\) A number of assumptions underlying the aim of “saving lives”, however, must be investigated.

Two assumptions underlie the purpose of “prevention” through disclosure. Firstly, the “partner at risk” is assumed to be HIV negative at the time of disclosure for otherwise, disclosure would not prevent infection. Secondly, if disclosure is made, it is assumed that the partners will adopt safer sex practices, have no further sex, or end their sexual relationship. If they continue with “risky” sexual practices, disclosure would not attain its objective.

The laudable aim of prevention cannot be served if the present partner (or future partner) is already HIV positive at the time of disclosure. However, any attempt at establishing the partner’s HIV status at the time of disclosure does not feature in the Guidelines procedure. Such an attempt would for example entail having an interview with the partner before disclosure of the tested person’s status, advising the partner that she is at risk of having contracted HIV, and urging her to undergo an HIV test. Only once the test result shows the partner to be HIV negative may the partner legitimately be informed of her partner’s status, as the purpose of prevention will then clearly be served. If the partner tests HIV positive, disclosure will either be too late (in that infection by the tested person has already occurred), or would serve no purpose (in that the partner would not have been infected by the tested person – her current partner – but by someone else, and could have infected the tested person herself).

The gendered nature of disclosure, and the presumption of blame through first disclosure, therefore comes into play here. If it necessarily follows that the HIV status of a woman who does not want to disclose is revealed to her partner, the disclosure may more likely lead to the end of the relationship or domestic violence than to prevention.

Perhaps it is impossible for the health care worker to go through the whole process of disclosure to a partner due to practical complexities, such as lack of time, co-operation by the tested person and consent for the test by the partner. Withholding information about the tested person’s status while requesting a test will often also be more apparent than real, as the partner will be left in no doubt as to the cause of the health care worker’s concern. However difficult to accomplish, it is only under these circumstances that a rational link will exist between disclosure of HIV status and the aim of prevention of sero-conversion.

It may be argued that the above analysis is overly individualistic and leads us into the very trap of which the judges in *Bernstein* warned. It may thus be countered that, rather than viewing this question through an individualistic prism, one should work with trends and probabilities. Accordingly, it may be contended that even if there is no proof that a specific partner is uninfected, it is probable that most partners under such circumstances will be uninfected. The problem with such a generalisation is that HIV infection depends on a multiplicity of factors, making a “model” situation almost impossible to postulate. In any event, as a matter of constitutional analysis, the party relying on the limitation bears the onus of satisfying the requirements in section 36. This may prove to be difficult, if not impossible.

Should it be established that the partner is HIV negative, it must still be shown that the second assumption, a change in conduct or an end to the relationship, will or is likely to occur. As possibilities abound, it is difficult to generalise. A couple married for many years, with children,

---

\(^{116}\) See eg Blackbeard, M “HIV/AIDS: The right to privacy v the right to life” (2002) 65 *THRHR* 232, who argues that a disclosure made to a sexual partner is justifiable “on the ground that right to life must outweigh the right to privacy” (at 241).
may decide to remain married but to refrain from sex. A recently married couple, intent on having children, may decide to take the risk and continue with unprotected sex. An unmarried couple in a short-term relationship may decide to end their relationship. Two people involved in occasional sexual encounters may decide to face the risk of infection. Prevention as a goal is considerably eroded in at least three of the four situations, due to the tenuous effect of the disclosure on the subsequent conduct of the two partners. Again, the onus of proving the link between limitation and purpose, which lies with those invoking the Guidelines, is only to be met by a generalised picture of what is more likely to happen in a relationship. There is little proof that most sero-discordant couples will necessarily engage in risk-minimising behaviour, or end their relationships.

If the relationship breaks down, there seems little guarantee that the tested person will not pursue other relationships without informing those individuals of his status. In so far as it exists, the initial duty to disclose, therefore, would not affect subsequent relationships. Perhaps the greatest risk lies with the infected and rejected person, who may pursue future relationships on the basis of deception. Should this be the case, disclosure may have the very opposite result to that intended, viewed not from the partner’s individual perspective, but from that of society.

The second aim of disclosure, that of ensuring access to medication, also relies on a series of assumptions: that the partner does not know her HIV status; that she will have herself tested as a result of the disclosure, will test HIV positive, having been infected by the current partner, and will thereafter get access to effective medication. If, in a particular case, one of these assumptions is not correct, the link between limitation and purpose falters. Even if all the other assumptions are fulfilled, access to medication remains problematic in a society where government-funded antiretroviral treatment is available only at limited, mostly urban sites.

Another question arises: Are the two objectives identified above contradictory, because the first (prevention) requires the partner to be HIV negative, while the second (access to medication) requires her to be HIV positive, or are they supplementary? Seen from an individual viewpoint, they are contradictory, as one person cannot be both HIV positive and negative at the same time. It should be established in which category each partner falls, in order for her to benefit from the disclosure. From a more communal vantage point, on the other hand, it may be argued that the category “partners” will, without being tested, logically comprise two sub-groups – HIV-positive and HIV-negative persons. When one adopts this perspective, the two aims of disclosure are not mutually exclusive, but supplementary: In respect of the HIV-negative women, the aim of prevention is served; in respect of the HIV-positive partners, the purpose of accessing medicine may be fulfilled.

If access to medication is to come into play, disclosure should be followed by the partner’s positive test result. In other words, treatment becomes necessary when it is too late for prevention of infection. In relation to these assumptions, two main questions arise. Firstly, was it the tested person who infected the partner or someone else? Evidently, this will depend on the circumstances, but it can certainly not be taken for granted in a society with a prevalence rate of close to 28%, that infection has occurred in the present relationship or as a result of sex with the present partner. HIV manifests itself mostly in the sexually active segment of the population, those most likely to engage in more than one relationship over time, and those more likely to enter into marriage, and bear children. Viewed broadly, it may be assumed that 28% of those in relationships who are most “at risk” are already HIV positive. Proof of a more or less 3 in 4 probability that the partner was infected by the tested person is not likely to serve as a strong enough link between disclosure and the aim of providing access to medicine to a partner infected by the tested person. It is true that the need for medication also arises even if the tested person did not infect her, but someone else. However, the disclosure is
set in circumstances that almost dictate the assumption that if the partner tests HIV positive, it would be due to the tested person. Obviously, it is also possible that the tested person contracted HIV from the partner. This will not be resolved medically. So, disclosure may reveal to the partner her pre-existing condition or status. How this is played out depends to a great extent upon the power relations within the relationship.

Secondly, disclosure for the purpose of accessing medication only makes sense if there is a real possibility of accessing medication that could reverse or at least halt the progress of the HIV attack on the immune system. Formulated in these terms, a debate is opened. Is the purpose of securing access to medication only served by providing access to triple therapy, HAART? Or is it sufficient to state that the informed partner will now take steps to improve her health, will get access to dietary supplements, and will react quicker to the appearance of opportunistic infections? It is suggested that this aspect will depend on expert evidence at the time, but that in principle there should at least be substantial benefit from accessing the national health care system. In the absence of an effectively functioning health care system providing access to such benefits, the link between disclosure and its benefits are seriously called into question.

Another assumption of disclosure is that there is a partner to disclose to. Disclosure differs from contact tracing where all past sexual partners are sought and informed that they may have been exposed to HIV infection. It seems that the Guidelines do not address the unmarried sexually active person who at the time of the test result has no specific partner. It is much more difficult to establish the veracity of any information in this regard, without requiring the health care worker to adopt the techniques of a private detective. The suggestion here is not that the Guidelines should be extended to comprise contact tracing but merely highlights the limited reach of the Guidelines in attaining the goal of prevention.

Finally, the measures proposed in the Guidelines are likely to undermine the aims sought. In a society where an HIV-positive person is stigmatised and ostracised, people are reluctant to subject themselves to HIV tests. Indeed, not all individuals suspecting themselves to be at risk of HIV will go for a test. If testing necessarily entails disclosure to sexual partners, reluctance to being tested is only reinforced. In the process, efforts towards protection and ensuring access will be impaired. From this perspective, the solution lies not in testing, but in generally educating the population about the risk to all sexually active people.

Are there less restrictive means than disclosure to attain the same purpose?

Thought must be given to the possibility that there are less invasive measures that may match the effectiveness of an obligation to disclose someone’s HIV status. First and foremost is the general awareness and understanding of the public about the risk of HIV infection. Resources have to be prioritised not only to raise a general awareness, but also to cultivate an acute understanding and appreciation of personal risk and collective responsibility, rather than relying on a compulsory disclosure, which will further burden an already overburdened health care system. Allocating resources in this way simultaneously privileges communal interests above individualistic concerns and protects the rights of the individual from excessive intrusion.

If a right or discretion to disclose is allowed, it should be formulated in precise and circumscribed terms in respect of the person to whom the health care worker may disclose, the time allowed for self-disclosure, and the duty of the partner not to disclose to third parties, even after the relationship with the tested person has broken down.

It must be clarified whether disclosure is only made to the present sexual partner, with past and future sexual partners being excluded, as they are not in immediate danger of being infected by the tested person. The net is cast too widely if disclosure is allowed or required to an amorphous body of past contacts or future partners.
One may pose the question whether the harsh effect of the measures could be mitigated by allowing the tested person time before the health care worker discloses. It seems harsh and unrealistic to expect someone who has just been diagnosed to take a rational decision about informing third parties about his status. An HIV-positive diagnosis places one face to face with one's own immortality, especially when AIDS is still regarded as a death sentence, and is likely to unleash powerful emotions of fear and anger, as has been illustrated in the research. The tested person should be allowed some time to come to terms with the news, and to negotiate an initial form of acceptance, before being threatened with exposure through disclosure.

The study illustrates that the main problem with disclosure is gossip. The Guidelines leave open the possibility of blameless rumour mongering, particularly as concerns past partners. The Guidelines should therefore impose a duty upon health care workers to notify the newly informed party of the duty not to disclose the tested party's HIV status to third parties. Admittedly, the enforcement of such a system would certainly be problematic and resource-intensive.

5.7 Conclusion on section 36: The tilting of the scales

In conclusion, placing a duty on health care workers to disclose the HIV status of their patients does not pass constitutional muster.

Such a duty prima facie infringes a number of important rights, such as the right to privacy, dignity, security of the person and equality. Important in an inquiry as to the reasonableness of the expectation of privacy is the use of the information provided for a particular health-related purpose for a different purpose (disclosure to third parties). Although none of these rights are absolute, or should serve to insulate the individual from society, such a duty constitutes a serious violation that can only be justified if a compelling interest is served by the least invasive means possible. Some laudable objectives are invoked to justify the limitation occasioned by a duty of disclosure. On closer inspection of the assumptions underlying these objectives, it transpires that the link between the limitation and its stated purposes is quite tenuous. Many of the problems associated with the obligation to disclose are practical, arising from the rupture between the idealised system of health care on which the Guidelines are based, and reality. The Guidelines assume a traditional “family” physician who takes care of an individual, within a family context, on a relatively constant basis. Paradoxically, this model assumes on the one hand a collectivity (the family as health care unit) but is on the other hand also very individualised, concerning itself with the sexuality of individual family members. In reality, the health care system has become depersonalised and commodified. A long-standing relationship of care with a patient is the exception rather than the rule. There are also less intrusive means to attain the legitimate objectives of protection and treatment access.

5.8 Is the situation different if both partners are treated by the same health provider?

Is the situation different if a doctor treats both the infected and the affected parties? In this regard, the decision of Australian courts in PD v Harvey is a good starting point. In that case, PD and FH were two individuals who were involved in a relationship. At the outset, they engaged in protected sex. After their relationship progressed in time and seriousness, they agreed to be tested for HIV and to share the results of the tests with one another.
In November 1998, they attended a joint consultation and HIV test at the Alpha Medical Centre, in Sydney. Dr Harvey, the physician who performed the test, provided little to no pre-test counselling. In particular, the issue of whether the two individuals would share their results was not raised. Dr Harvey also failed to indicate on the patient charts that they wanted to enter into a serious relationship, and that they had attended the clinic together. They gave blood samples and were told to return in a week’s time.

PD returned to the clinic alone. She was informed that she was HIV negative and received her pathology results from the receptionist at the Medical Centre. She also asked the receptionist for FH’s results. This request was refused on the basis that the information was confidential.

After receiving FH’s test result, Dr Harvey phoned him with the news that he had tested positive for HIV. A short telephone discussion followed. None of the issues arising from the prior joint consultation were discussed. The doctor did not ask FH if he intended to tell PH of his status, nor did he counsel him to do so. The doctor referred, made an appointment and urged FH to attend a specialist HIV clinic. FH returned to the clinic to collect his test result, and spoke with Dr Chen, the clinic director. Dr Chen did not raise any issue pertaining to the relationship with PD, or any other partner, but urged FH to attend a specialist clinic. FH failed to keep the appointment made for him.

PD contacted FH, informing him about her negative result, and offered to show him her pathology results. He replied that he accepted her word, and told her that his test was also negative. She insisted on seeing the result. When they met, he showed her a negative test result.

PD and FH subsequently moved in together and married. They began engaging in unprotected sexual intercourse. By that time, PD had also become HIV positive. By January 2000, she discovered FH’s HIV-positive status when she found a copy of his “genuine pathology report”. She returned to the Alpha Medical Centre, demanding to know her husband’s test results. After the visit to the Centre, PD underwent another test, which revealed her HIV-positive status. In February 2000, she gave birth to their HIV-negative child. The marriage between PD and FH subsequently dissolved.

PD approached the New South Wales High Court, suing both Dr Harvey and Dr Chen for loss of life expectancy, loss of earnings, loss of earning capacity, “lost years”, future medical expenses, as well as future care for herself and for the child conceived with FH. PD alleged the medical practitioners breached their duty of care by failing to take adequate steps to protect PD from HIV infection. PD argued that she was a patient at a practice that knew or should have known that she was engaged in unprotected sex with an HIV-positive person of whose status she was unaware. PD also submitted that the medical practitioners failed to inform her of FH’s HIV-positive status.

The Supreme Court found that the medical practitioners had indeed breached their duty of care for they ought to have taken steps to “ensure that, as far as was legally possible, PD was aware of the danger she was in”. The Court investigated options open to the doctors, and criticised their failure to have explored any of the possibilities. In particular, the Clinic should have kept better cross-referencing and should have followed up the referral of FH to the specialist clinic. Had they done so, it would have become clear that FH was dishonest and posed a risk to PD. Under those circumstances, the doctors should have made use of their competence under the Public Health Regulations to inform the Director-General. In this way, PD would have been informed that she might be at risk without the doctors breaching their duty of confidentiality to FH. The failure of medical practitioners to disclose FH’s HIV-positive status to PH did not constitute a breach of the duty of care. The Court specifically observed that the medical practitioners “were not at liberty to tell her of the information they had concerning FH’s HIV status”. Thus, there was no obligation on the doctor to
tell the sexual partner of someone who had tested HIV positive of the test result.

In its judgment, the Court endeavoured to retain the sanctity of doctor-patient confidentiality, while reaching a desirable outcome. However, it is arguable that one undermines the other. The desired outcome, confirming a duty of care to ensure that PD was aware of the risk, ultimately perforates the cloak of confidentiality. Even if the doctor does not breach the duty by directly informing PD, the ultimate consequence of his report to the Director-General is that PD is informed of the risk. Even if the source of the risk is left unnamed, she will be in no doubt about the true state of affairs. The elaborate procedure may be more nuanced, but it is also more costly, time-consuming and cumbersome, and only serves to keep an illusion of confidentiality intact.

Subsequently, an amendment to the Privacy Act 1998, which entered into force in 2001, forces doctors to put the issue of shared information on the agenda at the time of an HIV test. In terms of this legislation, Dr Harvey would have been compelled to raise the issue during their joint consultation, and the parties could have agreed, or would have disagreed explicitly.

An inquiry about the constitutionality, under South African law, of such a provision has to take into account that the practical difficulties in securing disclosure are less pronounced when both the tested person and partner are patients of the same practice. This link between the limitation and its purpose may be weighed differently if that is not the case.

5.9 A duty on the part of a sexual partner to disclose HIV status?

Interviewees expressed two different opinions about the question as to whether an HIV-positive person has a duty to disclose that fact. According to a member of the SAPS, an HIV-positive person has the right to remain silent about his or her status, “and there is no one who can force him or her to disclose to other people”. This represents an individualistic view of an absolute right to privacy and autonomy, juxtaposing the interests of the individual with those of the community. Others felt that if a spouse keeps quiet about her HIV status, it “would be like she was cheating him”. This represents a more relative view of the right to privacy, deriving from the relational nature of rights. It was also reported that some HIV-positive women were assaulted after their names and status had been published in the biography of a prominent South African politician. During legal proceedings requesting an interdict against the publication, lawyers for the politician argued that there was an obligation on the women to inform their sexual partners of their status.

If non-disclosure by an HIV-positive person who is aware of this fact to a sexual partner at risk of infection gives rise to civil and criminal liability, one may derive a duty on the part of an HIV-positive person to disclose his or her HIV status to a sexual partner. The question is therefore whether such liability exists.

As far as delictual liability is concerned, there is only one relevant South African reported case, Venter v Nel. In this decision, the Court accepted – without having heard argument from both sides – that a sexual partner who knows his HIV-positive status, who does not inform his sexual partner and who has unprotected sex with her, has acted unlawfully and is liable for damages. If the matter had been properly argued, at least two requirements of delictual liability would have posed problems. It cannot be assumed that the sued person caused the infection of the partner. It may be very difficult to prove such causality, since the infection of a person cannot be traced to a specific individual. Also, it seems inappropriate to earmark the person’s amorous advances as an intention to harm. It may be correct that he foresaw a possibility

---

119 FG 14 (Police Hammanskraal), F2.
120 FG 13 (Tshwane Youth Development), M5.
122 1997 (4) SA 1014 (D).
of harm, and accepted the risk – but one may also argue that the risk was so remote that he dismissed it as negligible.\(^{123}\)

Another contentious element of delictual liability is unlawfulness. If a person does not disclose his status, but engages in safe sex (for example by insisting on the use of a condom), it is in my view quite clear that the requirements of unlawfulness and intention would be absent. Similarly, these elements are absent when the person does disclose his status, but the other person consents to sex – safe or otherwise. Consent to unprotected sex with an HIV-positive person constitutes acceptance of risk of injury. USA states that have specific HIV-related criminal offences provide that mutual consent is a defence to a charge of infecting another. Such an approach is in line with the intimate nature of sexual relationships, the autonomy of the individual and the voluntary assumption of a risk. Especially given the relatively remote chance of transmission, it is not necessarily the case that such consent would be contra bonos mores. Consent to the risk of HIV infection is not totally dissimilar from entering a boxing ring, where a risk of serious bodily injury is imminent and even death is not excluded.

Unlawfulness seems to depend on the nature of the relationship between the sexual partners. Non-disclosure to a consenting adult “one night stand” is arguably not unreasonable, in the light of the mutual consciousness of risk that may be assumed in an area and era of high prevalence. The legal convictions of the community may play out differently if there is a significant age difference, a definite power relationship where one partner is dependent on the other, or where there is some inducement to sex. Non-disclosure to a marital partner may be unlawful on the basis of the trust and companionship that result from the marriage itself.

Even if the law stated that there is a duty on a wife to disclose to her husband (and the other way round), the constitutionality of such a legal rule has to be considered. The factors identified above once again enter into the equation: What purpose is served by compelling spouses to disclose? Arguably, these objectives would be the prevention of infection of the HIV-negative partner, timely access to medication for the as yet unsuspecting partner if he tests positive, and care for the HIV-positive spouse even if the other spouse tests negative. The problems that have been highlighted before, such as the fact that both spouses may be infected already, the spouses do not engage in sexual practices that pose a risk of HIV, medication will not be available, and care for the positive spouse should not depend on disclosure, also apply in these circumstances. The likelihood of disclosure coinciding with harm or violence also needs to be discounted. A blanket rule that an HIV-positive spouse has to inform the other spouse of his or her HIV status would be unconstitutional, as it leaves no room for any of these factors. The determination as to whether a spouse has such a duty needs to be evaluated on a case to case basis, taking into account all the relevant factors, while giving due weight to the right to privacy, and other relevant rights.\(^{124}\)

Non-disclosure differs from fraudulent misrepresentation. An action for damages differs from an action based on fraudulent misrepresentation, when the issue is not the omission to tell, but a false answer to a pertinent question. In the USA, one of the most famous cases demonstrating civil liability for failure to disclose HIV status is the one brought against Rock Hudson, a well-known movie star, by Marc Christian.\(^{125}\) Christian, one of Hudson’s sexual partners, successfully claimed for damages on the basis that Hudson had known of his HIV-positive status, but denied that fact when Christian queried him (and his personal secretary) about his HIV status. In this case,

\(^{123}\) It is estimated that the probability of infection through unprotected vaginal intercourse is around a maximum of 2 infections per 1 000 exposures (a probability of 0,002 per single exposure) (Whiteside, A and Sunter, C (2000) AIDS: The challenge for South Africa 11).

\(^{124}\) As required under sec 39(2) of the Constitution, which requires courts to promote the objectives of the Bill of Rights when developing the common law. See also Neethling, J et al (2001) The law of delict at 70.

Christian did not become HIV positive himself. The Court thus awarded damages for emotional distress. It is important to note that Hudson’s explicit denial constituted a fraudulent misrepresentation.

What about criminal liability as a source of an obligation to disclose? An HIV-positive person who knowingly engages in unprotected insertive or receptive anal or vaginal intercourse arguably meets the elements of the crimes of attempted murder, culpable homicide, assault with the intent to do grievous bodily harm or assault. The elements of attempted murder may all be met – the sexual act of infection, unlawfulness, based on the *boni mores*, and intention in the form of *dolus eventualis* (the foresight and acceptance of harm). The possibility that the alleged perpetrator would be guilty of assault with the intent to cause grievous bodily harm comes up against similar reservations. The difficulty with a charge of culpable homicide is the element of causation, linking the HIV infection with the ensuing death. The advantage of culpable homicide is that intention (and knowledge of HIV status) is not required. In any event, if all the problematic elements are satisfied, there may be convictions. A conviction on charge of assault seems likely. Disclosure of HIV status by the “suspect” should in all these instances constitute a defence. As the other complexities discussed above show, it does not follow, from that fact alone, that there is a general duty on an HIV-positive person who knows his or her status to disclose that fact to all sexual partners.

In the end, these circumstances underline the limits of formal law and institutional human rights imperatives. A relationship between two persons is of a highly personal nature, and is based on autonomous personal choices in a complex world essentially beyond state control. A regime of coercive partner notification by sexual partners and spouses will only collude in creating an illusion that legal measures have the capacity to secure the community.

### 6. Death

Does the position change subsequent to the HIV-positive person’s death? May the pathologist or other person performing an autopsy, for example, reveal the status of the deceased? May newspapers publish rumours about the cause of death? Does the doctor-patient privilege cease to exist? Is there a right to privacy and dignity beyond the grave?

In principle, legal personality ends at death. Rights and obligations cease to exist. In so far as the law provides for the disposal of bodies and the sanctity of corpses and graves, it does so in the public interest, and perhaps in the interest of the “generic” dead. These laws do therefore not imply that rights are kept alive after death. In so far as the law protects the assets of a deceased person (for instance through laws of succession or laws regulating intellectual property rights), it does so in the interest of heirs and creditors. Again, the existence of such laws does not suggest a continuation of the subjective rights of the deceased.

It has been said that traditional African society is a collection of the living, the dead and those yet to be born. The dead, therefore, have a continuous presence; they form part of the gallery of ancestors, and are believed to determine the fate and destiny of the living. The communal nature of death is underscored by the nature of funeral ceremonies, which may last for many days and involve the extended family and the community as a whole. In an individualistic society, someone’s death is a much more private affair, and marks closure and final farewell rather than continuity and lasting bonds.

This implies that the defamation of the dead should be regarded differently in a communal society and in a more individualistic setting. Writing about another African

---

126 In respect of an HIV-positive person who unknowingly transmits the virus, it may arguably be difficult to establish *dolus eventualis*, as that person’s actions are directed at maximizing pleasure rather than harm.

context, Dieng observes as follows: 128

In as much as solidarities in Africa center in the family ... it is clear that defamation is necessarily contrary to family interest ... and anything which spoils a man’s name threatens to reflect on his family. Protection of the family is therefore an important factor in the law of defamation. ... The person defamed need not be a living member of the family. The logic of maintaining the name of a man means that he can be defamed in his death.

However, even if this sentiment is correct and applicable to parts of South African society, the legal personality of the deceased cannot be revived. A solution is to accept that a person cannot claim for defamation of the dead, as such, but that he or she may claim if the defamation of the dead person reflects negatively on him or her (the living person who claims). Such possible claims may be limited to specific family members, and may be limited to a specific time period after the death of the deceased.

The question consequently is: How does a revelation about someone’s HIV status impact negatively on someone? It is submitted that the only relevant negative impact is the inference that the surviving person (spouse or sexual partner) may be infected with HIV. Any other inference or negative impact on the child, parent or family member of the deceased is too remote and should not be the basis for a claim for defamation. However, even allowing such claims (implying HIV infection) would only perpetuate the stigma associated with HIV.

As far as the duty of the doctor to disclose is concerned, the confidential doctor-patient relationship should remain intact as far as possible after the death of the patient. The question must be: What benefit is there to the surviving spouse or sexual partner to know the HIV status of the deceased? There are two main possibilities. If the survivor is HIV negative, such knowledge serves no purpose at all. However, it would be best, under appropriate circumstances, for the surviving HIV-negative spouse to undergo a test once the window period has expired. If the surviving spouse or partner is HIV positive, this fact will be revealed to him or her when she undergoes an HIV test. In both instances, the survivor should undergo an HIV test after the expiry of the window period to establish his or her status. Evidently, the very same result can be achieved without any information about the deceased being revealed. Surviving spouses or sexual partners who have reason to believe that they had been at risk should have themselves tested if they want to have certainty. In any event, they should be concerned about their status when the deceased falls ill, rather than waiting until his death, if they are really concerned about their own health. The moment of death is, for this purpose, irrelevant. I therefore argue that there is no duty to reveal the status of the deceased. Indeed, the wish of the deceased during life not to reveal his status should be respected unless it can be shown that disclosure will serve a compelling interest, rationally linked to the limitation.

The 1999 abortive attempt on notification of AIDS also proposed the disclosure to the "person responsible for the preparation of the body" of someone who had died of AIDS. Such a disclosure is misplaced. The death of an HIV-positive person may be due to many factors that are not AIDS related. Requiring information about "AIDS deaths" would therefore make little sense. Universal precautions should be taken to ensure continuous safety. If these are taken, there should be minimal risk of infection to the person preparing the body. In any event, if the person died of natural causes, there should be very little cause for concern about the risk of infection to those who prepare the body in the setting of traditional culture.

7. Conclusion

The results of the study indicate that stigma on the grounds of HIV and AIDS is rife. For many, AIDS equals death. This close association with death has stigmatised AIDS as a death sentence, allowing PLHAs to be banished from human concern and compassion. However, there are some signs that the tide is turning. People are starting to accept people who are living with HIV and AIDS because they “are starting to realise that it is too common, that in one way or the other one is infected or affected”. There is also greater openness about sex. The lack of a cure has reinforced the link between death, helplessness and stigma. Accessible treatment may reduce stigma and will strengthen the image of AIDS as a manageable chronic condition. Ultimately, death remains the great equaliser, and as dying becomes closer and more personal, the stigma seems to reduce. It is not clear from the study whether this is due to “stigma fatigue” setting in, or to a change in consciousness, but there is a sense in which death may restore community to society, opening the possibility of an environment in which disclosure may be less threatening and stigmatising.

“Shared confidentiality” is premised on a mythical and idealised traditional society. As this study shows, contemporary South African society contradicts this image. “Shared confidentiality” should rather make room for “shared responsibility”, in terms of which all ill people are treated with caution and care, and all sexually active people act with risk-consciousness.

Disclosure of HIV status is rare. But stigma and disclosure interface. On the one hand, a breach of an individual’s right to privacy may lead to the disclosure of that person’s HIV status, thus stigmatising that person. On the other hand, confidentiality may reinforce stigma, as the lack of disclosure perpetuates HIV/AIDS as a “terrible secret”.

Stigma claims to serve an expansive and amorphous conception of community. Major inroads into the privacy and other rights of the individual, manifested in shared disclosure without consent, and a duty on health care workers and sexual partners to disclose may find justification in this ill-defined notion of society. In this view, human rights are seemingly at odds with community.

However, as has been shown, the Constitution is not deaf to the calls and interests of the community. In deciding whether the Constitution allows for a duty to disclose, one has to steer a course between the extremes of the trumping capacity of individual rights and the priority of communal concerns. This discussion has shown that the human right to privacy does not privilege the individual above the community, nor does it impose an individualistic view of society. Such a view has no place when we face a disease so all-embracing in its impact on the community as AIDS. The section 36 limitation analysis invites communal interests in the form of societal goals that limit rights to override these rights if these goals are sufficiently important and clearly linked to the achievement of these objectives. In this process, the goal of coercive partner notification is not the protection of a vague and amorphous community, but the interests of identifiable individuals who are in a relationship with the HIV-positive person. The constitutional analysis thus allows for a relational interpretation of rights, without eroding rights by making them subservient to a generalised and emotive claim of “saving lives”.

Seen in this light, the conclusion is that there should not be a single, blanket and general coercive regime imposing obligations on health care workers or partners. It is accepted that there is a right to disclose, but no general duty to do so. The determination of this duty is in the first instance dependant on the nature of the relationship. In so far as the Health Professions Council’s Guidelines imposes an obligation on health care workers to disclose

129 F4 in FG 5 (clinical supervisors).
130 KI 21 (social worker).
a patient’s HIV status to a sexual partner in all instances, the Guidelines are unconstitutional. If they are permissive, allowing a discretion, one factor should be added, namely the danger of violence to which disclosure will or is likely to expose the tested person. This will allow the health care worker to consider all the relevant factors, and not be constrained to disclose once he finds that partner may be at risk. Still, the Guidelines should add that there is no duty on the health care worker to disclose, and that he or she cannot be sued for not disclosing to a partner.

It is arguable that spouses may be required to accept joint consultations, and that a stronger argument for duty to disclose HIV status derives from the marriage bond. However, also this duty should not be absolute, but should be dependent on the fear of violence or other forms of “reprisal”.

The law deals insufficiently with stigma and its consequences. Although the Constitution provides for the rights to privacy and equality, it makes no specific provision for non-discrimination on basis of HIV. With the exception of the relatively privileged sphere of employment, laws do not unequivocally state that HIV is no basis for discrimination or that stigmatising an HIV-positive person may constitute hate speech. Although the law provides remedies for victims of stigma, in the form of defamation and crimen injuria, some of the main problems, such as gossip, are not adequately addressed. In this regard, stigma brings law to its limits, and maybe to its knees.

Arguments for compulsory disclosure imply that society has failed to make voluntary disclosure possible. Instead of putting the blame on the individual, society should interrogate itself. The argument is that enough (individual) disclosures will open the eyes of society to the need for compassion towards those who are HIV positive, consequently leading to the de-stigmatisation of HIV/AIDS. Such an approach expects the individual to bear the whole burden, and to be sacrificed in an effort to bring society to its senses. This expects too much of the individual. Rather, society should be expected to change its views, and communal and collective efforts should be lodged. AIDS stigma is a problem of the many who are unaware of their status, not of the few who know they are HIV positive. Its solution lies in the collective, not the individual effort. Respect for privacy does not detach the individual from a stigmatising society. On the contrary, it allows him or her to be a member of society where disclosure of HIV status often amounts to a negation of societal membership. A respect for rights therefore strengthens and supports society itself.

131 See Strauss, SAS (1991) Doctor, patient and the law, who expresses the view that doctors definitely have a right to disclose this information to a spouse, but adds that there may well be a duty to do so too (at 105).
CHAPTER 4

HIV testing and voluntary counselling in the context of stigma

Ncumisa Nongogo
Lawyer and training coordinator, AIDS Legal Network
1. Introduction

The discovery of AIDS in 1981\(^1\) has posed complex human rights, legal and ethical, public health and even scientific issues\(^2\) internationally. On the one hand, some of the initial responses by states were characterised by a paranoia to identify all those infected or likely to be infected with HIV and exclude them from society. Proponents of this approach argued that the best way to control the epidemic is to invoke the traditional mandatory public health policies, for example compulsory HIV testing and isolation of those infected with the virus.\(^3\) On the other hand, there has been an increasing endorsement of the importance of the need to protect the rights of those infected by HIV or those vulnerable in order to protect the broader community. This approach has been termed the “AIDS paradox”.\(^4\) While the latter approach is entrenched in the global response to HIV/AIDS, human rights imperatives have in some instances been used as a justification for government’s inaction. In the case of \textit{TAC v Minister of Health},\(^5\) the South African government’s arguments against the extension of the Prevention of the Mother-to-Child Transmission (PMTCT) programme was a lack of capacity, among other things to provide HIV testing and counselling in all public health facilities.

While the discourse on these and other aspects of HIV/AIDS continues into the third decade of the HIV/AIDS epidemic, significant advances have been made in understanding the science of HIV, the creation of enabling and supporting environments, development of new diagnostic technologies and increased access to HIV and AIDS treatments. It is in this context that some writers have been calling for new approaches to, among others, HIV testing and an effective response to the HIV/AIDS epidemic – highlighting that it is the “obligation of the states to take all the necessary measures to prevent epidemics”.\(^6\) An effective response includes fundamental issues such as access to adequate health care services and the realisation of human rights.

The Tswelopele Research undertaken during 2004 also recognises that “HIV/AIDS is a human rights issue because groups that are already vulnerable to human rights violations – such as women, children, sex workers, and those living in poverty – are unable to realise their rights … [W]omen, and particularly young women, are more vulnerable to infection if they lack access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. People living in poverty often are unable to access HIV care and treatment, including antiretroviral and other medications for opportunistic infections.”\(^7\)

Many argue that similarities exist between public health and human rights.\(^8\) This chapter discusses how informed consent, in the context of HIV testing, is not only important because of human rights concerns but is also a requirement for effective HIV/AIDS prevention and treatment programmes. The terms “informed consent” and “voluntary counselling and testing” (VCT) have been used interchangeably in this paper, as counselling is the process of obtaining informed consent. This chapter specifically explores issues related to HIV testing, the impediments to testing and responses needed to scale up VCT programmes. It further attempts to highlight some of the challenges in ensuring effective informed consent.

---

1. Du Bois, RM; Branthwaite, MA; Mikhail, JR and Batten, JC “Pneumocystis carinii and cytomegalovirus infections” (1981) 2 The Lancet 1339.
5. \textit{TAC v Minister of Health} 2002 (4) BCLR 356 (T). See also Minister of Health v TAC 2002(5) SA 721 (CC).
7. Ch 1 above para 1.
8. The objective of public health and human rights is to protect the wellbeing of people. Human rights promote and protect the rights and dignity of all who are at risk of being discriminated against. Public health promotes health with an emphasis on those who are vulnerable to threats to their physical, mental or social well-being. Harvard School of Public Health AIDS, Health and Human Rights; An Explanatory Manual – the public health rationale states that to ensure effective HIV prevention and care, public health must include an explicit commitment to respect human rights and dignity.
important debates and the relationship between human rights and public health, and in doing so it explores how stigma and discrimination impact on HIV testing and informed consent, and explores recommended ways forward in changing the face of the epidemic.

2. Stigma and Discrimination

Even as countries over the world have struggled to respond to the HIV/AIDS epidemic, issues of stigma, discrimination and denial have been among the most poorly understood, yet most unyielding, dilemmas facing the development of public health and education programmes. Peter Piot, the director of UNAIDS, described “the continuing challenge” in the fight against HIV/AIDS at the Programme Coordinating Board in December 2000 as the need for “renewed effort to combat stigma.” He further explained that “effectively addressing stigma removes what still stand as a roadblock to concerted effort to concerted action, whether at a local community, national or global level, so action against stigma ramifies across every single aspect of HIV work.”

Many resources have been made available to deal with the HIV/AIDS epidemic and many advances have been made. However, stigma and discrimination continue to pose major problems in the fight against HIV/AIDS. A USAID concept paper states: “The problem is a difficult one, because underlying the apparent universality of the problem of HIV/AIDS-related stigma, discrimination and denial there appears to be a diversity and complexity that makes it difficult to grasp in a programmatically useful way.”

To understand exactly how and when stigmatisation happens we need to perhaps explore where stigma originates from and how this impacts on accessibility of health care services.

Through his analysis, Goffman traced stigma back to the classical Greek era where it was described as “a brand placed on outcast groups”. He defined stigma as “an attribute that significantly discredits in the eyes of society and reduces the person who possesses it”. He further argues that a stigmatised individual is seen to be a person who possesses “an undesirable difference.”

On the other hand Parker and Aggleton argue that “Goffman’s work has been used in much HIV/AIDS research as though stigma were a static attitude rather than a constantly changing social process and has seriously limited the ways in which stigmatisation and discrimination have been approached in relation to HIV/AIDS.” They argue instead that stigma and discrimination can only be understood in relation to power and domination.

Throughout the developing world, allegiance to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they appear, are social phenomena linked to the actions of

---

12 Ch 1 above.
15 Parker and Aggleton (2002): “In our view stigma plays a key role in producing and reproducing relations of power and control in all social systems and cause some groups to be devalued and other to feel that they are superior in some way and therefore it is linked to social inequality.”
whole groups of people, not the consequences of individual behaviour.\textsuperscript{16} However, the Tsvelopele Research Project found that the foundation stones of AIDS-related discriminatory human rights are issues related to lack of knowledge and fear.\textsuperscript{17}

For our interventions to be effective we need to understand both the historical and present context in which the stigma takes place, as well as the type of stigma used by individuals, families and communities.

Michel Foucault wrote about the relationship between culture or knowledge, power, and the notions of difference. He speaks about the regimes of power embedded in different knowledge systems, and the forms of control exercised by such systems over individual, as well as social, bodies.\textsuperscript{18} In this regime, he argues, physical violence and coercion increasingly gave way to what he describes as "subjectification" or social control exercised not through physical force, but through the production of conforming subjects and docile bodies.

In the course of the Tsvelopele Project the issue of culture and knowledge were raised. Many people living with HIV/AIDS believe that sexual promiscuity is on the rise, and that this is due to too much sexual information available to young people, and a breakdown of cultural values, which leads to increased sexual behaviour (FG1, FG3).\textsuperscript{19} In many societies there are certain expectations that women should behave in a specific way and in the absence of the "norm", women are labelled or marginalised. One of the participants in a group discussion had this to say: "if there is a bash in a certain area and your friends will come to you and say let's attend the party. When you reach that place you start drinking and you end up being drunk and now you get a loose girl". It is clear that at this level gender inequality plays itself out and women are judged if they frequent parties and shebeens and are labeled as "loose girls" or "bad girls".

A few years ago Gugu Dlamini disclosed her HIV status in her community, which resulted in her violent death. Many people are still reluctant to access health care services or to disclose their HIV status because of fear of discrimination and stigma or in extreme situations, fear of violence.

It is argued that stigma and discrimination are seen as social processes that are linked to the production and reproduction of structural inequalities. Identifiable social actors seeking to legitimise their own dominant status within existing structures of social inequality deploy stigma. We need to give greater attention to the broader political economy of social exclusion, which in turn could help us think about contexts and functions of HIV-related stigma, more adequate strategies for responding to HIV/AIDS, as well as linking this to the era in which AIDS became a reality for the global community.\textsuperscript{20}

Together with the issues explored above we also have to look at the language we used in our messages when talking about gender and stigma before the advent of HIV/AIDS\textsuperscript{21} and how this relates to stigmatisation and discrimination presently. Understanding the origins of poverty, together with the increasing polarisation between rich and poor in both the so-called developed and so-called developing world.\textsuperscript{22}

\begin{flushleft}
\textsuperscript{16} UNAIDS (2000) "HIV and AIDS-related stigmatisation, discrimination and denial: forms, contexts and determinants." Research Studies from Uganda and India (Prepared for UNAIDS by Peter Aggleton.)
\textsuperscript{17} Ch 1 above.
\textsuperscript{19} Ch 1 above.
\textsuperscript{20} Parker and Aggleton (2002): “The key characteristics of this period, from roughly the late 1970s to date, has been a radical restructuring of the world economy linked to the growth of what has been described as informational capitalism. These transformations has been characterised by rapidly accelerating processes of social exclusion, together with an intensified interaction between what might be described as ‘traditional’ and ‘modern’ forms of exclusion. Among the most vivid processes described by recent research have been the rapidly increasing feminisation of poverty, together with the increasing polarisation between rich and poor in both the so-called developed and so-called developing world.”
\textsuperscript{21} Parker and Aggleton (2002): “In short, stigma related to social unacceptable gender behaviours has intersected with sexual stigmatisation and HIV-and AIDS-related stigmatisation in mutually reinforcing ways, and it is impossible to fully understand or respond to AIDS-related stigma without taking these interactions into considerations. It is equally clear that the poverty – often in tandem or conjunction with racial oppression – has become one of the major sources of vulnerability as well as of stigma as HIV/AIDS epidemics have ‘matured’ in recent years. While the stigmatisation of poverty, and the role of stigma in deepening and reproducing economic exclusion of the homeless, the landless, the jobless, and other marginalised groups is particularly poorly understood, the fact that such forms of pre-existing stigmatisation have interacted with, aided and abetted HIV- and AIDS-related stigmatisation is clear and well documented”.
\end{flushleft}
stigma we can see how HIV and AIDS are used as a justification for excluding people.

De Bruyn\(^{22}\) has identified five factors contributing to AIDS-related stigma: (1) the fact that AIDS is a life-threatening disease; (2) the fact that people are afraid of contracting HIV; (3) HIV and AIDS association with behaviours (such as sex between men and injecting drug use) that are already stigmatised in many societies; (4) the fact that people with HIV and AIDS are often thought of as being responsible for having contracted the disease; and (5) religious and moral beliefs that lead some people to conclude that having HIV or AIDS is the result of a moral fault (such as promiscuity or “deviant” sex) that deserves punishment. Thus, putting an individual at a disadvantage on the basis of some quality or capacity is happening at various levels in the community, as individuals, as women, in education and schools, religious institutions, employment, financial and health care facilities.

During focus group discussions people living with HIV/AIDS (PLHAs) related their personal experiences of how people in the community are treating them when accessing services and how this relates to fear and lack of knowledge.

“People do not believe that one can be HIV positive and still be healthy”.\(^{23}\) PLHAs described incidents in which community members did not believe that they were positive and said that they must be getting paid to say that they are HIV positive.\(^{24}\) One PLHA described being told that her body would give in and she would become tiny and thin like an infant (FG1), indicating a lack of knowledge about the progression of HIV to AIDS. Another PLHA recalled a story in which a doctor pointed to her swollen lymph glands at a funeral and told others that she looked like she had HIV. This was enough to start gossip about her status (FG2)\(^{25}\).

Our understanding of these factors should inform our interventions, services and educational programmes. The creation of an enabling environment where people can exercise their rights is critical, as it is this as well as the other points mentioned that would assist in the normalisation of the epidemic.

### 3. HIV/AIDS and Testing

An important component of the normalisation of the epidemic is knowing one’s HIV/AIDS status. To achieve this people need to be tested and for testing to be successful it must happen in an enabling environment. It is the latter that has to be explored. In the 23-year history of the epidemic many advances has been made as expressed earlier, but many challenges still exist regarding HIV/AIDS and testing.

AIDS was first discovered in the United States in 1981, mainly in gay men who were already a marginalised community. The common conditions among these men were a rare type of pneumonia and Karposi’s Sarcoma. HIV, therefore, fed into the existing stigmatisation of gay men. While it later became clear that sexual orientation was not a key determinant of HIV transmission, the stigma remained.\(^{26}\)

In South Africa, the first case of AIDS was diagnosed in 1982. Again, it initially affected gay men, although later it became clear that the South African epidemic is largely heterosexual.\(^{27}\) HIV/AIDS continued to be associated with promiscuity, foreigners (especially from neighbouring countries), blacks and sex workers. For many years, people believed HIV/AIDS was a problem for “others”, thereby creating a false sense of security. The national response to HIV/AIDS began in 1988 when AIDS Training and Information Centres (ATICs) were established.\(^{28}\)

---


\(^{23}\) Male, FG1.

\(^{24}\) Female PLHA, FG2.

\(^{25}\) Ch 1 above.


\(^{28}\) Tallis, J “AIDS is a crisis for women” (1998) 39 Agenda 7.
The results of complacency can be seen in the exponential increase of HIV infections during this period.

The initial response was largely medical, neglecting other socio-economic determinants of HIV. HIV testing was largely not available and most people who wanted to know their HIV status went for blood donations as the blood transfusion services began screening donors for HIV. When the HIV tests became available testing was largely without informed consent and in many cases used to discriminate against those who tested positive.

The Tswelopele Research Project confirmed this through the focus group discussions and informant interviews: “Most people, including health care workers and PLHAs, shared stories of being tested without giving consent, without pre- and post-test counselling, or being told, ‘you are HIV positive and you will die’.”

Even though HIV testing without informed consent is still happening today, as long ago as 1992 a collaborative process was initiated to develop a new national AIDS strategy. This culminated in what was then called the NACOSA AIDS plan. Important in this plan was the recognition of human rights aspects of HIV, including that testing be done with informed consent. This plan was streamlined into the National AIDS Plan. During this time human rights abuses against PLHAs were prevalent and included testing without informed consent and denial of life cover by the insurance industry (resulting in refusal of housing loans by some financial institutions), pre-employment HIV testing, unfair dismissal from employment on the basis on one’s HIV status and refusal of access to health care.

These phenomena were attributed to a number of causes, including lack of information about HIV/AIDS itself, the “blaming” attitude, fear, association of HIV/AIDS with death, the sensational reporting of HIV/AIDS in the media and the portrayal of PLHAs, as illustrated in the following view:

I think it’s lack of knowledge. Education is all over but people will ignore that education and they don’t care. If people know more about this disease they won’t have a problem, they won’t differentiate between TB and other treatments but what makes it different is that people lack knowledge about this disease. They only know about the prevention but they don’t know all the details.


The South African legal and policy framework has over the years evolved to offer some of the best human rights protection in the world. However, the problem remains the gap between practice and official policy.

4.1 Common law

Under South Africa law, obtaining informed consent has long been established as a requirement for all forms of medical treatment, either for diagnostic or treatment purposes (both invasive and non-invasive). Our courts have clarified why informed consent is a legal requirement for medical treatment. In Stoffberg v Elliot the Court noted the following:

In the eyes of the law every person has certain absolute rights, which the law protects. They are not dependent upon statute or contract, but they are rights to be respected, and one of the rights is absolute security of the person ... Any bodily interference with or restraint of a man's person which is not justified in law, or excused in law or consented to, is a wrong ...

---

29 FG1, FG3, FG4.
31 Focus Group Discussion Male PLHA, FG1.
32 McQuoid-Mason, DJ and Strauss, SA "Medicine, dentistry, pharmacy, and other health professions" (1999) 17 LAWSA para 195.
33 Stoffberg v Elliot 1923 CPD 148.
However, our law recognises that in certain circumstances it is not necessary or even practical to obtain informed consent from the patient. These circumstances would include instances where there is a law requiring treatment to be given without informed consent, in emergencies, in the case of people with limited capacity to give consent, from guardians in the case of minors, and in the case of mental illness.\(^{34}\)

### 4.2 Ethical and professional guidelines

The Guidelines of the South African Medical and Dental Council (now the Health Professions Council of South Africa) and the Medical Association of South Africa have clearly articulated the need and process of obtaining informed consent, in particular for HIV testing purposes.\(^{35}\) Despite these guidelines, some doctors continue to test people without consent which has also contributed to the anti-testing sentiment.

### 4.3 The Constitution

There is also a constitutional duty to protect rights as enshrined in the Constitution.\(^{36}\) These include the right to human dignity, the right to privacy and, importantly in this context, the right of freedom and security of the person, which includes the right of persons to make decisions on reproduction, security and control over their bodies and not to be subjected to medical or scientific experiments without consent.\(^{37}\)

### 4.4 The National Policy on Testing for HIV\(^{38}\)

This policy incorporates some of the legal provisions on informed consent and provides guidance on how they should be applied in the context of testing for HIV. It lists circumstances under which testing may be conducted and further clarifies the definition of informed consent. This policy places an emphasis on the process of counselling which should accompany HIV testing.

### 5. The Realities: HIV Testing and Informed Consent

There is still no universal access to HIV testing. A combination of factors contribute to this situation. On the one hand, there is the lack of political will to make services for HIV/AIDS generally available.\(^{39}\) This is a result of denial of the problem of HIV in South Africa, which surfaced around 1999.\(^{40}\) On the other hand, because of stigma, discrimination and importantly lack of access to health (in particular to HIV treatment), there has been a questioning of the value of knowing your HIV status if “there is nothing that can be done” or if people are “sent home to die”.\(^{41}\)

The absence of, or inadequate provision for counselling and HIV testing is counterproductive. It serves the interests of denialists,\(^{42}\) as it shifts the issues of HIV/AIDS on the agenda, justifying the inadequate allocation of the necessary resources and implementation of programmes to prevent new HIV infections and treat HIV/AIDS.

---

34 Note 11 above.
35 HPCSA Guidelines 2001, The HPCSA Guidelines say that doctors should not do an HIV test on a person without informed consent. “The patient should be given information regarding the purpose of the laboratory test; what advantages or disadvantages testing may hold for him or her as a patient; why the surgeon or physician wants this information; what influence the result of such a test will have on his or her treatment; and how his or her medical protocol will be altered by the information. The psychosocial impact of a positive test result should also be addressed.”
37 Sec 10, 14, and 12 Act 108 of 1996.
39 Health Systems Trust & Gauteng Department of Health; Integration of HIV/AIDS Care and Support into Primary Health Care in Gauteng Province, July 2002.
42 Ibid.
While our law and policies have entrenched the right to informed consent there are in practice constraints on obtaining informed consent. In many respects informed consent and in particular the process of counselling has been seen as a barrier to wide access to HIV testing. Some have argued that there is no need to obtain informed consent before an HIV test. We, however, know that the importance of HIV testing cannot be over-emphasised.

A doctor interviewed during the Tselopelile Research Project had this to say: 43

OK, in the clinic where I work ... there is a counsellor who does the counselling. So no person can have the test without being counselled. All will go for proper counselling. This is one of the biggest problems and if you think you’ve got to see in the morning, we are talking about nurses in the ante-natal clinic and out of 20 or 30 women, if you spend, a proper counselling will take 20 minutes at least. We haven’t got the time to do it. It’s unrealistic to think that they can. Add that on to an already extremely busy worker ... All the sick patients arrived that day, they are going to do all the administration including checking the medicine, order medicine and all the administration, nurses off duty ... Anyone who wants to add to that during the 20 minutes of counselling on 30 patients per day, it’s unrealistic, totally unrealistic. Even with a dedicated counsellor, he can’t do it. There is not enough time to do it, to do it properly.

HIV testing and counselling with informed consent cannot be over-emphasised as it presents an opportunity to access prevention, treatment and care services. It encourages people who are HIV negative to remain negative through behavioural change interventions. On the other hand, those who test positive can also access services to prevent and treat opportunistic infections associated with HIV/AIDS, monitor their HIV progression and when necessary, access medicines to treat HIV/AIDS. 44 This in turn leads to improved quality of life, as well as prolonging the lives of people living with HIV/AIDS, thus reducing the devastating impact HIV/AIDS is having on our society.

Some workers and patients indicate that they have been tested without their knowledge; thus it is important for people to know how and when HIV testing occurs. Currently, HIV testing and counselling services in South Africa are offered in the circumstances mentioned below.

5.1 Testing for diagnostic and treatment purposes

This is usually offered at the suggestion of health care workers when HIV testing is clinically indicated – to make a diagnosis or for treatment purposes. In many cases the patient would already show some symptoms of HIV/AIDS. Whilst it is important that HIV testing and counselling is offered at this time, sometimes it is not offered to clients or it is being done inadequately, as reflected in the following observation: 45

And what about consent? Is it really informed consent? I don’t think so, I don’t think so because basically they are sick, they are in pain, they want to get better. And then they stay with you for five minutes and nine times out of ten you are sure that this consent form, they are going to sign it. Even you the person who does the counselling, you know it. The other thing is whether this pre-test counselling, is it done the way it should be. Do you think so? If the people need their rights, do you think, I don’t know.

---

43 Ch 1 above para 4.4.2: Focus Group Discussion, Clinic Doctor, KI15.
44 Available at www.who.int/hiv/topics/vct/testing/en/.
45 Ch 1 above Social Worker, KI21.
46 See note 5 above.
5.2 Testing as part of prevention of mother-to-child-transmission of HIV

VCT is offered as a part of the PMTCT programme. This is not only important to the women who will need to make decisions about their health generally, as well as reproductive health in particular, but is also an entry point for the prevention of new infections in babies.

Initially this service was offered at only 18 sites but was extended to all sites in South Africa with the capacity to offer these services as a result of the court case instituted by the Treatment Action Campaign against the Minister of Health. Despite the court order PMTCT is still not universally accessible in South Africa. This is another missed opportunity for VCT as its universal access could reach more than 90% of women who use the public antenatal services. At this level women receive education and are screened for a number of conditions. VCT in this context also warrants criticism as some argue that because it is offered to women only and not to their partners, it perpetuates the stereotype of women being seen as vectors of HIV, and even puts them in difficult positions of needing to inform their partners against a background of high gender inequality and violence against women.

5.3 Testing after rape, sexual assault or accidental exposure to HIV

Although no statistics exist on the extent of VCT carried out in these circumstances, there is nevertheless an opportunity to increase access if these incidents are reported in time and people know that they will receive the related services and support as a matter of routine. In South Africa this was well demonstrated when government prioritised calling for legislation that would allow survivors of sexual violence to get perpetrators tested for HIV without consent, which in itself has been widely accepted as a fair balance between the rights of the survivors and those of perpetrators, but without committing to offer them access to post-exposure prophylaxis (PEP) which would be an immediate need in the circumstances. It was not until later that a policy to offer PEP at government expense was implemented. Again, anecdotally we know of incidents where survivors of sexual assault are still not offered VCT and or PEP. The full potential of increased access to these services is limited due to low levels of reporting of rape cases in particular.

5.4 Employment

Before 1998 it was legally possible for employers to test employees or job applicants for HIV on condition that the employee concerned consented to the test. While there was a grey area around the desirability of such testing, our constitution and labour laws still prohibited discrimination on the basis of HIV status. Much HIV testing done in these circumstances was by and large conducted for discriminatory purposes and was not concerned with the health of the individual.

There are examples of reported as well of unreported cases of testing without consent resulting in discrimination against people who tested HIV positive. Sustained lobbying to end discrimination in this area resulted in the passing of the Employment Equity Act, prohibiting discrimination, inter alia, on the basis of one’s HIV status. The two main provisions relating to HIV in the Act are that firstly, it prohibits HIV testing for employment purposes except where the testing is authorised by the Labour Court and secondly, it prohibits discrimination based on one’s HIV status or perceived HIV status. Undoubtedly this was one of the major achievements in the fight against discrimination. Despite this prohibition in law

---

47 C v Minister of Correctional Services 1996 (4) SA 292 (T); Hoffmann v SAA 2001 (1) SA 1 (CC).

testing without consent and discrimination against people with HIV/AIDS in the workplace continues.

In *NASUWU obo Zulu v Chen* the applicant, who was employed as a child minder, refused to undergo HIV testing and was then dismissed for insubordination. In the arbitration proceedings the Commission for Conciliation, Mediation and Arbitration (CCMA) commissioner found that the dismissal was unfair and awarded compensation to the employee. The commissioner further ruled that refusal to undertake an HIV test did not amount to insubordination as the insistence by the employer that the applicant test for HIV was not a lawful instruction.

The extent of the prohibition of HIV testing in the Employment Equity Act has also been a subject of debate, with some people arguing that the strict reading of the Act prohibits all forms of testing in the workplace, including VCT. This resulted in the first case of *Joy Mining Machinery v NUMSA and Others*, where the applicant sought permission from the Labour Court to implement a VCT programme in the workplace. The Court granted them the order. The essence of the debate has concerned the application of the purposive approach in interpreting the Employment Equity Act, that the Act sought to prohibit was testing that could lead to discrimination and that it is not necessary to obtain consent in the case of, for example, VCT. The position has been settled by the subsequent court case of *Ndebele Mining Company (Pty) Ltd*.

Because of discriminatory practices by some employers there has been a strong awareness raising regarding the rights of employees to refuse HIV testing for employment purposes.

5.5 Testing for insurance purposes

Insurance companies as a matter of routine now require applicants to undergo an HIV test to obtain life insurance. Their protocol says that this testing should be offered with pre-test counselling at the least. Again we know that most insurance companies do not offer HIV counselling, as it is generally understood. They provide written materials on HIV/AIDS to applicants to read before signing the consent form. The emphasis is on signing the consent form, presumably to protect the companies against any legal claim for testing without informed consent. In most cases an HIV-positive result causes the rejection of life cover to people living with HIV/AIDS or refusal to pay out the benefits of a policy if the deceased died of an HIV-related condition. Whilst this practice is defended by the industry it unfortunately associates HIV with discrimination. On the other hand, the tragedy is that the insurance industry tests thousands of people every year. Most of these people are not offered counselling and it is again a missed opportunity for VCT.

5.6 Testing for clinical trials

The Department of Health Guidelines for Good Practice in the Conduct of Clinical Trials in Human Subjects in South Africa recognises the following circumstances where HIV testing may be required in clinical and epidemiological research, namely:

- epidemiological studies, e.g. sentinel surveillance on pregnant women
- observational studies, e.g. the effect of long-acting progestins on the risk of HIV transmission in women
- drug trials, e.g. to establish efficacy and safety, and
- vaccine trials.

---

49 NASUWU obo Zulu v Chen [2002] 5 BALR 511 (CCMA).
51 Ndebele Mining Company (Pty) Ltd: Ex Parte J 1466/01 (LC) – the Court granted authorisation for the running of a voluntary HIV testing and counselling service, thus implying that they have jurisdiction to grant authorisation for both employer- and employee-initiated HIV testing.
52 Available at www.doh.gov.za.
As early as 1977 the Medical Research Council developed Guidelines on Ethics for Medical Research. These have been updated over the years. The Guidelines on Ethics for Medical Research involving human subjects are clear. They place a duty on researchers to conduct scientifically sound research while acting in the participants’ interests and respecting and protecting the participants’ free will. Some guiding principles of ethics include respect for human dignity, autonomy, informed consent, the rights of vulnerable persons, confidentiality, and lack of harm, maximum benefit and justice.

Although no data exist on the number of people that are tested as trial participants, it can be assumed that this figure would constitute a significant figure in communities where these trials are held, especially phase III vaccine trials that usually involve hundreds of people.

6. Voluntary Counselling And Testing (VCT)

Almost all the HIV testing mentioned above is usually not patient initiated – it is offered because a person is sick, pregnant, raped, wants to apply for life insurance or is recruited to participate in a clinical trial. While these aspects are all important, VCT services need to access a critical mass of people who may not be reached in these ways.

In 1994, the government adopted the National AIDS Plan and, in 1999, the Department of Health developed the HIV/AIDS/STD Strategic Plan for South Africa 2000-2005. One objective of the Plan was to seek ways to address discrimination and human rights abuses of people infected and affected with HIV/AIDS. The priority areas outlined in the plan include: prevention; treatment care and support; research, monitoring and evaluation; and human and legal rights.

The Strategic Plan outlines improving access to VCT by increasing the number of voluntary HIV testing and counselling sites, as well as increasing the number of persons seeking VCT. The strategies included introducing counselling services in all new testing sites, expanding the use of rapid testing methods, and increasing the proportion of workplaces that have on-site counselling and testing services. The Comprehensive Plan for the Management, Treatment and Care of HIV/AIDS is seen as an “operational plan” for the Strategic Plan. The Comprehensive Plan has been operational for a year and includes many aspects relating to the treatment and care of people living with HIV/AIDS.

Essentially, almost all organisations, research agencies, governments and non-governmental organisations see VCT as a prevention strategy, a tool for promoting health and well-being amongst those who opt for the service, a means of psycho-emotional support, a process of informed consent, a tool to reduce stigma and a human right.

Based on these assertions the importance of VCT cannot be ignored; thus the debates and countless research undertaken to explore all these concepts.

However, research in South Africa has shown that very little that takes place in the name of VCT is in fact voluntary – a fact that undermines both prevention and supportive outcomes. At one district hospital in South Africa, for example, of 368 patients who were counselled and tested between January 1999 and May 2000, none had voluntarily presented for testing. All were referred by a doctor and were often in advanced stages of AIDS. The primary goal in such a context is the initiation of appropriate medical treatment rather

---

53 Available at www.mrc.ac.za/ethics/committee.htm.
54 MRC Ethical Guidelines on Medical Research.
than either primary prevention or the provision of psychosocial support.

Factors that influence the effectiveness of VCT programmes can also be ascribed to organisational dynamics, such as multi-tasking of health care workers and time constraints placed on the health system by the number of people visiting primary health care facilities. In Fawcett’s 2001 study, the average number of patients receiving consultations with health care workers was 6 per hour, averaging 10.4 minutes per patient. Fawcett contends that it is doubtful whether either coping or preventive messages can be conveyed in such a context.

While policies and laws are in place and the intention to roll out VCT programmes is clearly stated, in order to identify how the VCT campaign can be effective, the VCT campaign in South Africa will be reviewed.

6.1 Progress in the VCT campaign

A research study undertaken by Soloman, van Rooyen, Griesel, Gray, Stein and Nott checked the current status of VCT services in South Africa, provided an analysis and made recommendations for the promotion, development, and sustainability of VCT services at a national level. The questions posed by the study are important to ensure we understand where we are at present and where we go from here. Soloman et al examine what we know about VCT, the lessons we can learn and where the critical gaps can be found.

Solomon et al report that there is no clear picture on the implementation of VCT nationally. Indeed, there are many contradictions in studies and reports as to the current state of VCT in South Africa. Some government reports give the impression that VCT services are running smoothly and proficiently, and even exploring the possibility of expanding VCT facilities to non-medical sites. Other reports, however, acknowledge the inadequacies that exist within the VCT system. For example, “whereas enormous resources have been allocated from the time to build counselling services, HIV/AIDS counselling services in South Africa remain underdeveloped, constrained by issues of competence, policy obstacles, lack of co-ordination and lack of resources”.

A female in one of the focus group discussions in the research project relayed this experience: “it’s not easy to go for testing at some places. Because why, there are no ... there is no privacy because the office of counselling, you have to go for counselling and everybody knows that that office is for counselling and you have to walk in front of other people to that office. They counsell you and after counselling you, you have to go for testing and you have to go again in front of those people knowing, those people know that there you went for counselling, you go for testing. After getting the results if people are there they can see …”

When a clinic is busy, people who come in for tests may be turned away because of lack of personnel to perform the counselling and testing. The need for individual pre- and post-test counselling is seen as unrealistic in the already under-resourced and overburdened public health system.

On a more practical note, however, the July 2002 report on the Integration of HIV/AIDS Care and Support into Primary Health Care in Gauteng made a firm recommendation on what needs to be done to increase efforts in order to ensure that VCT becomes available to all persons seeking such services. The recommendations include: ensuring adequate staffing; increasing capacity for HIV/AIDS counselling and testing; improving clinical skills; additional training; guidelines and protocols; improving referral and networking; enhancing support systems to...
address issues of provider morale and motivation; monitoring and evaluation of HIV/AIDS care in the primary health care clinics; and co-ordinated planning and communication.\textsuperscript{61}

It should be noted that at the end of October 2004, the government released a progress report on the elements of the Report stating that “VCT service points increased nationally from 1 500 sites at the end of the previous year (2003) to 3 072 VCT points by the end of September 2004.”\textsuperscript{62} No analysis was given with regard to the effectiveness of the 3 072 VCT sites or the challenges that might exist with regard to resources, capacity or the number of users per site.

Solomon et al’s review indicates clear views on the expansion of VCT sites in that existing strategies have to be reviewed and adapted. According to statistics, HIV/AIDS seems to be on the increase, which might indicate that VCT plans are possibly not producing envisaged results.

An important point to note in this diaspora is that there are also conflicting views on the effectiveness of VCT as shown in a study in Uganda. In rural Uganda VCT had had no effect on sexual behaviour a year after VCT services had been provided.\textsuperscript{63} However, another study in Kampala research showed that clients who participated in VCT reported safer sexual behaviour as compared to those who have not been tested.\textsuperscript{64}

Solomon et al’s review of literature indicates consistently that VCT is more effective in facilitating behaviour change in those who test positive than in those who test negative. The other conclusion made is that VCT seems to be more effective if both partners are targeted, as opposed to one partner.\textsuperscript{65}

In order to achieve high rates of service users at VCT sites, the barriers to providing a quality VCT service must be examined. Solomon et al discuss internal and external barriers that prevent the provision of quality VCT services. Internal barriers relate to the implementation of the plan and service delivery of HIV testing and counselling and pertain to reviewing of those policies and strategies. The external barriers are related to potential users of the service, their communities, their perceptions and fears related to the disease, survival issues, partner violence, stigmatisation, fear of results and cultural factors.

It is argued that understanding these barriers and dealing with them when providing VCT services will assist in achieving the desired goals.

### 6.2 VCT and informed consent

VCT as a process of informed consent is defined as a service that provides a complete “package” of important information and that equips the client to make an informed decision about whether or not they wish to go ahead with the HIV test. This view emphasises the need for people to know and understand the process of testing fully in order to make a voluntary decision.\textsuperscript{66}

The National HIV Testing Policy and the Code of Good Practice on HIV/AIDS and Employment confirms this in defining informed consent as follows: “The individual has

---

\textsuperscript{61} Modiba, P et al (2002) "Integration of HIV/AIDS care and support into primary health care in Gauteng" Centre for Health Policy, School of Public Health, University of the Witwatersrand, Johannesburg.

\textsuperscript{62} Prevention and Communication: Progress report on the implementation of the comprehensive plan for the management, treatment and care of HIV/AIDS 21 October 2004, released by Dr Karly Chetty, Acting DG, DOH.


\textsuperscript{65} Individual VCT services in an African context would be most effective if they actively targeted men instead of routinely testing females. In African male-dominated societies VCT with men will have more impact on couples’ subsequent behaviour.

been provided with information, understands it and based on this has agreed to undertake the HIV test. It implies that the individual understands what the test is, why it is necessary, the benefits, risks, alternatives and any possible social implications of the outcome."

The challenge remains to ensure that this basic right is exercised for those individuals seeking VCT, and to provide capacity at service delivery points to make sure that informed consent is given by the client before HIV testing takes place.

Observation undertaken at the clinics during the Tsxelopele Research Project illustrated that there is little by way of confidentiality and a right to privacy in going for an HIV test. Most clinics do what they can with limited resources. Often the counselling takes place in a room that doubles as a medicines room, or storage space, with people coming in and out.

Female 3: It’s not easy to go for testing at some places. Because why, there are no ... there is no privacy because the office of counselling, you have to go for counselling and everybody knows that that office is for counselling and you have to walk in front of other people to that office. They counsel you and after counselling you, you have to go for testing and you have to go again in front of those people knowing, those people know that there you went for counselling, you go for testing. After getting the results if people are there they can see ...

In Botswana, prevention of mother-to-child transmission programmes, clinic-based group counselling, video sessions, and the use of “lay” counsellors and community-based counselling services are being used as a way to reduce the length of individual pre-test counselling sessions. However, some researchers feel that this type of pre-test counselling might put women under pressure to do an HIV test and that the waiting time is reduced with the rapid test. Another concern is that the client is given a limited amount of time to reflect on pre-test counselling and to make a considered decision to test.

The process of the test should be ethical, ensuring information about the purpose of the test, the benefits of the test, implications of a positive test result and links made to relevant treatment options and care are communicated during the counselling session. Ensuring that the confidentiality of the patient is maintained is critical.

6.3 VCT as stigma reduction

The South African government and many international agencies hold the view that normalising HIV/AIDS will reduce stigma. This means that if more people are tested and know their serostatus, HIV can then be treated as a “chronic” illness instead of it being viewed as a “death sentence”, thereby assisting in lifting the fear and stigma associated with HIV/AIDS. Indeed, Solomon V et al’s review confirms this position. The review holds the view that stigma is also linked to concepts of confidentiality and secrecy in the process of VCT and that confidentiality is a significant aspect in achieving the aim of drawing people in for testing with the aim of normalising HIV/AIDS as a disease.

The Department of Health also defines VCT as a free and confidential service.

However, as reported in the Gauteng study, health care providers felt that confidentiality is problematic in dealing with the disease as the secrecy assists in reifying the silence around the epidemic and the stigma associated

---

68 Ch 1 above.
with it. A tension remains evident in the literature review of Solomon et al regarding the role that confidentiality should play in the definition of VCT. Confidentiality in the view of our legislation and common law remain a fundamental right and should be respected. It would seem that the general problem is the emphasis on confidentiality as meaning “do not tell anyone”, rather than on counselling focusing on how to support a person to make a decision about openness.

6.4 VCT and human rights

VCT should not only be seen as a health service, but also as a human right. People have the right to know or not to know their HIV status. People have the right to be counselled and supported through both the decision to test and receiving their results. People have a right to be educated about HIV and its implications. This is not only seen as an essential medical intervention but also as an ethical and moral obligation in terms of the rights of the general population to access such services.

These rights and obligations are enshrined in our Constitution, guidelines, and policies. The government policy as outlined in the Strategic Plan 2000-2005 cites HIV testing as one of its strategic goals and describes VCT as the implementation of this goal.

The Tswelelele Research Project highlighted some important debates regarding HIV/AIDS and human rights. One person from a community-based organisation indicated that “the right of people not to disclose their status results in the spread of the disease. AIDS is not a human rights issue, nor is it meant to be”. He iterated the need for disclosure to prevent others from making the same mistakes.

7. Practical Challenges

There are many challenges in providing voluntary counseling and testing services. The disparities that exist between data available to make an informed assessment call for a proper review of what needs to be done. The Department of Health reports that the number of VCT sites increased from 1 500 in 2003 to 3 072 by the end of September 2004. On the other hand, Solomon et al identified only 495 VCT sites, with 359 that were operational.

It is important that we have fully operational quality VCT services available to all citizens in our country who need it, to ensure that we fulfill our goal of normalising HIV/AIDS, and reducing stigma and discrimination.

As reported in Solomon et al’s review, government is committed to implementing and providing VCT facilities to a large section of the population by consistently increasing the number of VCT sites over time, as well as making targeted interventions to ensure that underserviced areas will be the first to receive VCT services.

In expanding VCT services the requirements should not be underestimated. Research findings clearly outline the need for increased capacity among counsellors through continuous training. The staff that is currently employed in health care facilities usually has a dual role to play, including that of counselling. Due to shortages of staff or staff being overburdened, we need to look at counselors who can be drawn from NGOs and other organisations in the community. Regardless of the backgrounds of counsellors we need to ensure that a high-quality service is provided at all times.

Rapid HIV testing has been made available and is useful in places where there are no laboratory services available,

71 Solomon, V et al, note 65 above.
72 Ibid.
73 Ibid.
74 K14, FB4.
75 Available at www.doh.gov.za.
76 Modiba, P et al (2002) “Integration of HIV/AIDS care and support into primary health care in Gauteng” Centre for Health Policy, School of Public Health, University of the Witwatersrand, Johannesburg: “Of the 215 providers who have completed self-administered questionnaires, 58% had received some training in HIV/AIDS; 40% had been trained in HIV/AIDS counselling through the ATICCS.”
however, external quality control and supervision is needed for this type of testing to be successful. A good example of the use of rapid HIV tests is the Uganda AIDS Information Centre, where testing sites grew from a single site in 1991 to 51 sites in 2001 and they have been able to test more than a half a million people. On the other hand, caution should be exercised in administering rapid HIV tests. Time given to clients to consider information before consenting to a test is shortened, and consideration should be given to the quality of counselling with rapid tests.

7.1 Slow uptake of VCT and the need to treat

In 2003, the World Health Organisation and UNAIDS launched the “3 by 5” initiative which aims to provide antiretroviral treatment to three million people in developing countries by the end of 2005.

Expanding access to VCT, inter alia, is an imperative if we are to achieve these goals. The slow uptake of VCT services is a threat to the implementation of our comprehensive plan for the management of HIV/AIDS. Recently our Minister of Health reportedly said that people are not coming forward for HIV treatment and that she cannot force people to take HIV medicines. However, if we look at the research findings of a study conducted in Gauteng, we will see that there are various reasons why people might not come forward to be assisted.

Some of the users interviewed went to seek help at up to eight health care facilities. The reasons cited for this was that they either did not get their results when they returned to the clinic, confidentiality had been breached in the clinic, and users felt undermined by health care workers. Some users said they were lucky because health care workers listened to what they were saying and they (health care workers) were “taking note” of them.

These factors, together with issues such as accessibility, remain a great concern in the national strategy, as it has been stated widely that “knowledge of HIV status is the gateway to AIDS treatment and documented prevention benefits”.

Why is the VCT uptake so slow? Is it because issues such as discrimination and stigma are holding back people who need these services? The UNAIDS 2004 report says: “scaling up VCT includes strengthened protection from stigma and discrimination as well as assured access to integrated intervention, treatment and care services”.

Essentially scaling up of VCT services should include strategies that would inform people of HIV transmission; pre-test counselling principles; individual or group counseling concepts; the use of rapid tests; and follow-up counselling.

Factors associated with the demand for VCT should be examined more closely. Acceptance of VCT is high, but the actual demand is questionable. Likewise a stated intention to test is not equivalent to, but only a pre-condition for, undergoing a process of VCT and it is found that many do not come back for their results.

Another critical area to be examined in measuring our success in VCT campaigns is the number of people who return for their test results and the proportion of those who receive post-test counselling.

78 Ibid.
81 Fylkesnes, Haworth, Rosensward and Kwapa (1999) explored uptake of VCT in a general population sample of selected rural and urban areas in Zambia. Of those who said they wanted to test only 9.4% actually came forward to test and only half of those tested came back for their results. Fylkesnes, K; Haworth, A; Rosensward, C and Kwapa, PM “HIV counseling and testing: Overemphasizing high acceptance rates a threat to confidentiality and the right not to know” (1999) 13(17) AIDS 2469-2474.
82 Solomon, V et al, note 65 above.
7.2 Training of counsellors

The Comprehensive Plan states that government needs to ensure that provincial authorities designate co-ordinators responsible for STD and HIV/AIDS in every province and district to increase capacity at these levels so as to manage, organise, and implement the strategy. A Health Systems Trust study of four VCT sites indicates that training has been inadequate. The report indicates that only 58% of providers received HIV training, of whom 40% were trained in counselling and 10% trained in clinical aspects of HIV/AIDS. Respondents in the study requested more training: 66% in further skills in HIV counselling and 49% in skills in clinical management. It is clear that the findings of the report indicate that a range of skills is needed by health care personnel to ensure a quality primary health care service is provided to those who need it. In evaluating the clinical knowledge of providers, the majority of the respondents had a “fair knowledge” of HIV, whilst only 16% of the respondents provided all the correct answers, and 28% had poor knowledge. The report recommends that clinical skills of providers should be improved and additional training should be provided, especially in view of networking skills with community-based organisations.

Over and above the skills needed by respondents it is important to note some of the negative experiences reported in the study by service users. Indeed, negative experiences were more common. Service users usually disclosed their HIV-positive status to health care workers in the hope of receiving treatment; however, these disclosures led to despair by users who are often blamed for their HIV status. It was reported during the study that nurses frequently accused people living with AIDS of being “always sick” and often told them, “you will be like this forever”. The users also said that the clinic staff “is not quick in providing treatment, no matter how sick a person is.”

Training of counsellors in human rights, ethics and anti-discriminatory practices remains one of the most important practical challenges. If people access health care facilities or seek VCT services they should be assured that they would not be stigmatised or experience dis-crimination.

7.3 Orphaned children

The greatest tragedy of the AIDS pandemic is orphans who are left behind when either one or both parents die because of AIDS. UNAIDS estimates that in sub-Saharan Africa there are 12 million children who have been orphaned by AIDS and this number is expected to increase to 18 million by 2010.

In South African law testing of children under the age of 14 years has to be done with the consent of a parent or guardian. Testing of orphaned children and consenting to treatment of orphans poses an ethical dilemma as the current process is very long. This is particularly difficult in instances where children have not been placed in formal care, either in children’s homes or in foster care. Indeed, because of these deficiencies, the Wits Pediatric Working Group has had to apply to the courts to be granted an order to test children who have no parents or guardians.

Other important human rights issues relate to caregivers of children accessing grants for orphaned children. During the Tswelopele Research Project “the difficulty of accessing foster care grants for children, usually left in the care of grannies, was highlighted and this was due primarily to a lack of documentation. Thus, children were being cared for by grannies, on small pensions that were not enough.”

A social worker interviewed during the Tswelopele Research Project “expressed her frustration at the lengthy process

---

84 Modiba, note 82 above 22-23.
85 Modiba, note 82 above.
86 Modiba, note 82 above 48-49.
88 Reported at www.alp.org.za.
89 K12.
required by the legislation before the issuing of a grant, and indicated that they are working on applications received in 2002.\textsuperscript{90} She indicated that the community “does not understand the serious pressures that they were under”.\textsuperscript{91}

7.4 Youth

Youth are hugely at risk for HIV and constitute half of all new infections globally.\textsuperscript{92} The UN Secretary-General’s Task Team on Women, Girls and HIV/AIDS in Southern Africa found that both transactional sex and intergenerational sex have become the norm in many countries. It is found that young girls view older men as good partners or providers of luxury goods or educational opportunities. Many girls accepted goods such as clothes, jewelry, cell phones and perfume from older men to make them more desirable amongst their peers.\textsuperscript{93}

A study in Zimbabwe found that nearly 25% of women in their twenties were in relationships with men at least 10 years older than them.\textsuperscript{94} Girls generally formed long-lasting relationships with one partner, but many living with HIV were infected soon after they started having sex.\textsuperscript{95} A Zambian study showed that 18% of women who said they became sexually active within the last year were HIV positive. In South Africa, the Nelson Mandela study has shown that the HIV prevalence among girls aged 15 to 19 was 7% (compared to 4% among boys of the same age).\textsuperscript{96} These relationships are based on power and economics that leave girls vulnerable to abuse, exploitation, violence and HIV/AIDS.\textsuperscript{97}

Young people are at great risk of contracting HIV, but they are also the only hope we have of halting the course of HIV/AIDS. We need to ensure that young people are given appropriate tools to assist in changing the face of the epidemic. Access to confidential youth counselling and health services, the promotion of condom use and the protection of rights of young people are important prerequisites for lowering the prevalence of HIV amongst youth.

In Uganda, political commitment and active community mobilisation led to a dynamic youth movement concerned with AIDS. Between 1990 and 2000, HIV prevalence amongst pregnant teenagers (15-19 years) in Kampala fell from 22% to 7%. Delayed sexual debut, reducing the number of partners and increased condom use were all significant factors in this success.\textsuperscript{98}

The AIDS agenda for young people needs to translate the 2001 UN Declaration of Commitment on HIV/AIDS into concrete actions and include: creating a supportive environment, reaching those who influence youth, placing young people in the centre of the response, mobilising the educational system, mainstreaming HIV prevention and AIDS care for young people, addressing gender inequality and opening a dialogue on sensitive issues.\textsuperscript{99}

However, the greatest concern today is that most youth do not regard themselves at risk for HIV and continue to behave as if it only affects others. Our challenge remains to change this mindset among youth and develop strategies that will reduce infection amongst young people, especially young women.

VCT should be backed up by services such as those seen among young women in Khayelitsha. During 1999 the Provincial Department of Health in the Western Cape offered women AZT to prevent mother-to-child transmission of HIV. More than 1 000 women were on the programme. For women to be eligible for this

\begin{footnotesize}
\begin{enumerate}[\textsuperscript{90}]
\item K121.
\item Ch 1 above.
\end{enumerate}
\end{footnotesize}
programme they had to find out their HIV status. Most of these women would probably not have taken an HIV test had there not been an incentive of AZT should they test positive. This proves that back-up support services are important when providing VCT services. It was also stated in the Gauteng study that health care workers discouraged people from testing for HIV because there was no medication available.

We have discussed the challenges in obtaining informed consent and examined how some countries have overcome this, but the HST study highlights the hopelessness of service providers, and quotes one respondent as saying, “because you see the message is the same, there is no medication [referring to ART]. Even now if you can go to the local clinic more especially .... they will tell you that, hey ... there are sisters I know who will tell their clients that even the immune boosters won’t help you.” Nurses usually question HIV-positive patients presenting at the clinic for treatment, asking them, “What must we do? There is nothing we can do”.

These attitudes, described in the research, together with staff shortages and lack of understanding of the legal rights of clients remain major issues to be addressed. People will not use health care facilities or come forward to be tested if these issues are not addressed. If we want to enhance our public health outcomes we need to face those challenges that prevent us from obtaining informed consent and protecting the rights of people most vulnerable to HIV. Stigma and discriminatory practices in health facilities will prevent people from coming forward to use VCT and other health services.

8. What are the New Approaches?

In the third decade of the epidemic many advances has been made in understanding the factors that fuel the epidemic. Our understanding now dictates that we need to work towards ‘normalising’ HIV/AIDS, thus reducing stigmatisation of, and discrimination towards individuals living with the virus. This in turn will reduce the vulnerability of people infected and most importantly ensure a reduction in the prevalence of HIV.

Voluntary counselling and testing provide the opportunity to provide all these imperatives, including health promotion, prevention, psychosocial support, human rights and a reduction in stigmatisation.

However, much needs to be done to achieve these objectives as important human rights principles such as confidentiality are still seen as an impediment to achieve openness regarding the disease. This reinforces the point made earlier that if there is a lack of an understanding of stigma and discrimination and how this relates to power in different settings our efforts to normalise the epidemic will have very little impact. It is clear that much needs to be done to improve our current programmes.

9. Access to Services

The most important aspect of ensuring the normalisation of the HIV/AIDS epidemic is to provide accessible services to local communities. On the one hand, organisations in the private sector, civil society and government should work together to ensure that the services are available and accessible to people. On the other hand, it is crucial that health care workers are trained in human rights, health rights and counselling. Understanding issues such
as confidentiality, informed consent and counselling are critical to ensure an increase in the number VCT programmes users.

An overall analysis by Solomon et al summarises the following critical areas for programmes: VCT and counseling, research needs, upgrading of facilities, and monitoring and evaluation of monitoring sites. It seems that new approaches to counselling should be introduced in the next decade of intervention. AIDS prevention and support programmes will have to locate VCT more specifically and exactly as a much broader strategy for dealing with HIV/AIDS. This strategy must involve securing a better quality of life for all Africans in general and specifically it must include improvements in housing, education, health and gender equity. Finally, it must link VCT to adequate care, support and welfare services.

There is a lack of research specifically on VCT in Africa and this is reflected in the national development and implementation of VCT services. More research is needed to demonstrate the primary prevention efficacy of VCT, as the impact of VCT in longer-term coping is not enough – most of the support offered is in the context of disclosure on the lives of HIV-positive people. Research on the process of counselling should be undertaken. The research conducted in Africa is of a moderate to high quality – but problem areas exist – especially gaps in the reporting of analysis and results, and the poor rating given to the discussion of ethical issues.

An important issue highlighted by the Tswelopele Research Project is misunderstanding between community and health care workers, as well as lack of clarity as to whether access to treatment impacts on stigma and discrimination.102

There is recognition that there needs to be consistent and regular improvement of existing VCT services, as well as expansion to new sites. Activities that can strengthen existing sites are workshops, continual counsellor training workshops and a continual upgrading of the knowledge base about HIV and VCT. This continual improvement is seen to be a feedback learning process whereby stakeholders in the process of setting up VCT sites are continually able to contribute their experiences about what work or doesn’t work in the VCT environment.

Ensuring certain qualities and standards are maintained allows for emerging problems to be dealt with immediately, including ongoing supervision of counsellors and development of research tools for measuring VCT outcomes. Other factors should include the promotion and marketing of VCT facilities.

10. Conclusion

During the initial response to HIV/AIDS less emphasis was placed on the importance of knowing your HIV status. It is now clear that VCT is an essential component of HIV prevention, as well HIV/AIDS treatment programmes. With the number of new HIV infections rising, prevention is crucial. On the other hand, access to treatment for HIV/AIDS, the prices of medicines decreasing, access to rapid HIV tests and other diagnostic technologies, the 3 by 5 initiative – all are opportunities to offer HIV testing on a large scale, for all are interventions to change the face of the epidemic.

Many people have spoken out about their status and this has contributed to increasing awareness about HIV. Social mobilisation of communities in the fight against HIV, especially in South Africa, is also contributing to destigmatisation of HIV and creating a demand for HIV services, including testing. Thabo Cele summarises this when he says:103

---

102 Ch 1 above.
I have been living with HIV for many years. I choose to live openly, because I have a right to exist in society like any other person. I do not have to apologise to anyone for being HIV positive. As people living with HIV we have to lead the struggle for treatment ... the struggle against HIV-associated stigma, the struggle for a better life for ourselves and others. We have to organise ourselves in support groups.

The current debate on how to scale up HIV testing is not yet settled. On the one hand it is suggested that HIV testing should be offered routinely, with clients having an option of refusing the test, and on the other hand it is suggested that HIV testing be offered as a standard practice with informed consent and confidentiality.  

It is suggested that if we address all the impediments to HIV testing, including training of more counsellors, integrating VCT as part of all health services, developing infrastructure, encouraging openness, eliminating stigma and discrimination, and offering treatment and other support services, there will probably be no reason why HIV testing cannot be offered whilst respecting people’s rights to autonomy and privacy.

Confidentiality is not an impediment to creating openness about the disease. In fact, respecting the right to confidentiality will ensure that more people go for HIV testing and obtain access to health care services. Dealing with these challenges as well as promoting the VCT service will ensure that we create an environment where people will access VCT sites and thereby work towards reducing the stigma and discrimination that currently surrounds the HIV/AIDS epidemic.

104 WHO (August 2003).
CHAPTER 5

“Hey Miss AIDS, when are you going to receive your social grant?”

The right to have access to social assistance: HIV/AIDS and disability grants

Farhana Zuberi
Consultant, Centre for the Study of AIDS, University of Pretoria

---

1 Focus Group (FG) 2 (People living with HIV/AIDS).
1. Introduction

The transformation of South Africa from a country based on racial intolerance to a country that is democratic and inclusive has been more than a mere change in the political landscape. Rather, as the Preamble and founding principles of the Constitution make clear, there is a focus on social and economic development and a push to redress injustices of the past and "improve the quality of life of all citizens and free the potential of each person".1

The goal of eradicating poverty was expressed in the Reconstruction and Development Programme.4 A crucial part of building the caring nation envisioned there and in the Preamble to the Constitution is the provision of social security and, where applicable, social assistance to South Africans who qualify for it. Section 27(1)(c) of the Constitution proclaims that people have an access right to social security and social assistance, and section 27(2) in turn determines that this right must be realised progressively by the state, within available resources.5

In South Africa, and in other countries in the world, certain people living with HIV or AIDS (PLHAs) qualify for disability grants. The conclusions reached in the Tswelopele research study6 illustrate some of the difficulties and questions that arise with respect to access to social assistance in the form of a disability grant. In this paper, using the Tswelopele research study as a basis, I examine the right of access to social security for PLHAs and the unique problems and difficulties that arise with its implementation. First, in part 2 below, I describe the general treatment of "disability" in South Africa, and then examine the extent to which HIV/AIDS has been regarded as a disability, with special attention to it as a threshold to access the disability grant. In part 3 below, I describe the current structure of social assistance provision in South Africa and particularly the process in terms of which PLHAs gain access to the disability grant. In part 4 below, I turn to the Tswelopele research study, and, on the basis of some of the data gathered there, identify and describe some of the difficulties and consequences of PLHAs’ access to the disability grant. Finally, in part 5 below, I identify and discuss some issues for further research and investigation.

2. HIV/AIDS as a ‘Disability’ in South Africa

South Africa has various laws and policies referring to disability, which impact mainly in two different contexts, that of unfair discrimination usually related to employment, and threshold of access to social assistance benefits. In this section, I will outline some of the relevant laws and polices in South Africa, and then proceed to highlight some of the issues related to the definition of HIV/AIDS as a disability, a matter which is far from settled in practice in South Africa, especially related to threshold of access to social grants.

Section 9(3) of the Constitution lists disability as one of the prohibited grounds for discrimination. The Promotion of Equality and Prevention of Unfair Discrimination Act7 does not define disability but does prohibit discrimination on the basis of disability.6 The Employment Equity Act9 defines “people with disabilities” as: “people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into or advancement in, employment”.10

---

3 Preamble to the Constitution.
5 Sec 27(1) provides as follows: “Everyone has the right to have access to ... (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance. (2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.”
6 Ch 1 above; the study was undertaken by the Centre for the Study of AIDS (CSA) at the University of Pretoria. A report entitled HIV/AIDS stigma and human rights: A localised investigation of Hammanskraal communities is available from the CSA or at www.csa.za.org.
8 Sec 9. Section 34 states that the HIV/AIDS should be considered for inclusion as a “prohibited grounds”. Sec 6 lists prohibited grounds for discrimination, including both disability and HIV status.
10 Sec 1.
Disability Strategy,11 the White Paper issued by the Office on the Status of Disabled Persons in November 1997, recognises that there is no one accepted definition of disability, and that certain circumstances such as poverty exacerbate the situation of the disabled in South Africa. The White Paper uses the definition of disabled person from the International Labour Organization: "An individual whose prospects of securing and retaining suitable employment are substantially reduced as a result of physical or mental impairment".12

The issue of whether HIV/AIDS is a disability is not yet settled in South Africa, especially related to unfair discrimination in employment. While a distinction appears to be made in the White Paper and various laws, the Constitutional Court has not yet ruled on the matter. The White Paper excludes PLHAs from the definition of disability, unless or until there are serious physical manifestations of illness, stating that:

People who are HIV positive suffer from social discrimination similar to that experienced by people with disabilities. This does not, however, imply that they are necessarily disabled. For the purpose of the Integrated National Disability Strategy, therefore, they are not included in the definition of disability, except where symptoms, such as prolonged fatigue, interfere with their normal functioning.

Further, both the Promotion of Equality and Prevention of Unfair Discrimination Act and the Employment Equity Act make a distinction between disability and HIV/AIDS. In section 34 of the former Act, the Minister is directed to turn his mind to the inclusion of HIV/AIDS status as one of the prohibited grounds for discrimination. In the latter, section 6(1) lists prohibited grounds for discrimination that explicitly include both disability and HIV status.

In case law, the question as to whether HIV/AIDS is a disability was raised in Hoffman v SAA,13 a case pertaining to unfair discrimination in employment. In the case, the applicant challenged a decision of the national airline not to appoint him, an asymptomatic HIV-positive man, as a cabin attendant on unfair discrimination grounds. The attorney for the applicant had argued that, following the US jurisprudence,14 HIV/AIDS should be seen as a disability even when in an asymptomatic stage, as people with HIV are judged to be disqualified by reason of disability by others, even if they are fully capable of doing the job.15

However, the AIDS Law Project (ALP), acting as amicus curiae in the case, argued that HIV should not be equated with disability as this would lead to difficulties in future cases.16 The ALP used the Employment Equity Act, highlighting the differentiation of HIV and disability in section 6(1) and between "medical testing"17 and "HIV testing"18 in section 7, as examples that a distinction has been made between disability and HIV status. The ALP illustrated that under the Employment Equity Act, if HIV-positive people were included in the definition of people with disabilities, then affirmative action programmes would have to be put in place for them by designated employers, irrespective of their health status. Finally, the ALP submitted that:19

... HIV-positive persons are not disabled merely because of that fact ... Asymptomatic individuals are entirely capable of discharging employment

12 ILO Convention 159 concerning Vocational Rehabilitation and Employment (Disabled Persons).
13 CCT 17/00, 2000 (11) BCLR 1211 (CC), 2001 (1) SA 1 (CC).
14 In Bragdon v Abbott (1998) 524 US 624, the US Supreme Court found HIV to be a disability as it was progressive in nature and also because it impacted on major life functioning of the applicant, even if it is in the asymptomatic stage. Similar reasoning was followed in Canada, in Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montreal (City) 2000 SCC 27, where a 'handicap' was seen to include ailments that do not give rise to any limitations or functional disability. This case did not have to do with HIV status, but rather with small physical problems that did not significantly affect the ability to work of the persons involved.
17 Subsec (1).
18 Subsec (2).
19 Footnotes omitted. ALP Affidavit, para 35.
In January 2000, the Department of Social Welfare introduced the Ten-Point Programme to improve social welfare in the country. One of the priorities in the plan was service delivery to PLHAs, and HIV and AIDS were included as disabling conditions to the extent that HIV and AIDS impair the life of the person infected to such an extent that it is not possible for him/her to engage in employment.  

Technically, this means that a person will only become disabled once he/she is too ill to work, due to physical or mental impairment, and his/her illness is expected to last over a long period of time. This does not mean that a person is disabled as soon as he/she tests positive for HIV. However, as will become clear in section 5, there is confusion about PLHAs’ eligibility for grants.

3. The Social Security System in South Africa

Social assistance and social insurance make up the system of social security in South Africa. Social insurance is the system of contributory grants such as pensions and unemployment insurance benefits. Social assistance is the system of grants that are provided to people who are unable to care for themselves. The most common form of assistance is the old age pension, with about 1,9 million beneficiaries. The disability grant is the second largest programme in Rand terms, but smaller than the child support grant in terms of number of beneficiaries. By September 2003, a total of 6,5 million people received social grants at a cost of about R2,5 billion per month.

The importance of social assistance as a means of alleviating poverty is clear. In the absence of the current social security system in South Africa, 58% of house-
holds would fall below the subsistence line. With the current social assistance system, 48.5% of the population is living below the poverty line. In the absence of the social assistance system, an estimated additional 430 000 households or 1.6 million people would be living in poverty. The existing social security programmes reduce the average poverty gap by 23%. For example, the importance of the old age pension was recognised by the Finance Minister, who acknowledged that the majority of people living in poverty who are not white live in three-generation households and the grant is usually turned over for general family use. For black South Africans, each pensioner’s income helps five other people in the household.

The 1992 Act governs social assistance in South Africa and provides the framework for how people can access government assistance. The 2004 Act is meant to deal with some of the problems that have been recognised in the administration and payment of grants under the current system. This legislation makes provision for various types of grants, including the child support grant, care dependency grant, foster care grant, disability grant, war veterans grant, and the older persons grant. The amounts that are paid under these grants vary. Various conditions must be met for a person to qualify under each of these grants, and this most often includes a “means test” that examines the household assets and income in each family before a person is eligible to receive the grant.

Under the 1992 Act and in the 2004 Act, the definition of disability has not substantially changed. A disabled person is someone who, owing to a physical or mental disability, is unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance. According to the definition of disability, people with HIV become eligible for the disability grant when they are no longer able to work due to a physical or mental impairment and support themselves. PLHAs, like all others, are eligible for a disability grant only if certain conditions are met. In addition, the applicant must pass a ‘means test’. Currently, the disability grant is R740 per month.

27 Measured as R401 per adult equivalent in the Taylor Committee Report.
29 Economic Policy Research Institute The social and economic impact of South Africa’s social security system (September 2004) 31.
30 The poverty gap gives an estimate of the extent of poverty, by adding for each household, the amounts by which income falls below the subsistence line. However, the Taylor Committee also noted the need for a Basic Income Grant for South Africans, as it concluded that even if all benefits were distributed to everyone who was entitled to them under the current system, the poverty gap would only close by 37%. See p59 of Taylor Committee Report. This is supported by Booyzen, F; Bachmann, M; Matebesi, Z and Meyer, J (2004) The socio-economic impact of HIV/AIDS on households in South Africa: Pilot study in Welkom and Qwaqwa, Free State Province, where the study found that while a high proportion of the households benefited from one form of social grant or another, a relatively large proportion of poor households had never benefited from social grants (at 134).
31 Budget Speech, 1997/98.
32 The Act is accompanied by the South African Social Security Agency Act, Act 9 of 2004, which creates the South African Social Security Agency to administer social assistance management and payments.
33 For old age, it is R740/month; for war veterans, R758; for the child support grant, R170/per child under 7 per month; for the foster child grant it is R530. See Government Gazette No 26197, 26 March 2004.
34 The asset level for a single person is R266 400, and for a married person it is R532 800. The income limitation is for a single person R18 024 per annum and R33 384 per annum for a married person. Available at www.welfare.gov.za/Services/asset.htm
35 Sec 9(b) of the new Act and definition section of the 1992 Act.
36 The conditions that must be met to qualify for the disability grant include:
1. The person must be a South African citizen or permanent resident.
2. Must be resident in South Africa at time of application.
3. Must be between 18-59 if female and 18-64 if male.
4. The person has to consult a doctor and the medical report has to show that he or she is unable to support himself or herself. The examining doctor must be a government doctor or district surgeon, and then the Pension Medical Officer must approve the medical report. Under the 2004 Act, a panel will replace the Pension Medical Officer so that the grant is assessed in terms of both medical and social factors.
5. The person must have an incapacity that means he or she is unable to get any kind of employment. The illness or disability must be permanent, or at least be expected to last more than six months.
6. The person’s spouse cannot afford to support him or her and has also passed the “means test”. (This is a test that looks at the person’s financial situation: only people who earn less than a certain amount or who are unemployed will be allowed to receive the grant.)
7. The person does not live in a government-run institution, eg a prison, a psychiatric hospital, an old age home, a care and treatment centre, or a centre for drug dependants.
8. The person must not receive any other social grants.
To apply for the grant, a person must go to the local Department of Social Development or pension office, with several documents such as a bar-coded identity book, proof of income or value of assets (including the income or assets of one's spouse), and proof of marital status. The applicant will receive a form to be filled out by a government doctor at a public hospital. Usually the applicant must present him/herself to a panel made up of a health care worker, social worker and community member to have the application reviewed and approved. The process takes from 3 to 6 months. The grant can be backdated, under the 1992 Act, up to three months. Under the 2004 Act, the backdating will be from the date of application.

If the grant is refused, the government must provide reasons in writing. A person can appeal against the refusal, providing reasons why the grant should be given. This appeal should be in writing and should reach the Department of Social Development within three months of receiving the refusal letter.

The disability grant can be reviewed every year by the government, but the 2004 Act determines that only applicants who declare their means of income at the time of application must have an annual review. Those who have no means are only required to submit a life certificate on an annual basis to verify that they are alive. The Department can request a person receiving the grant to have a medical check-up with a particular doctor. If the doctor believes that the person is no longer disabled and can go out to work, then the grant can be stopped.

As the disability grant is for people who are unable to work, a person is not eligible for a grant immediately on becoming HIV positive, especially if he/she is still healthy or not suffering from any major illness. Rather, a person will qualify for the grant when he/she is too ill to work. This is usually when the person’s CD4 count is between 50 and 200, and/or he/she is suffering from a major opportunistic illness that is likely to last longer than six months.

To qualify for a disability grant on the basis of HIV status, an applicant has to disclose the results of his/her HIV test to an officer at the Department of Social Development, and to the doctor who must complete the forms. However, the right to confidentiality still exists, so the doctor or social worker cannot disclose the person’s HIV status to others without their consent.

The social relief from distress grant is available for an emergency situation, often while waiting for the processing of the disability grant, for up to three months. It is usually in the form of coupons for use at the supermarket. The amount received is deducted from the disability grant, once the applicant starts receiving it.

Currently, expenditure on disability grants is on the increase and this is a matter of concern for the government, which recognises that it will be unable to continue with the increased demand over the next few years. The number of disability grants has increased by 30% in the 2002/03 financial year, and 33.2% in the 2003/2004 financial year. This spending on social grants is impacting on the level of spending on other services such as health and education. The implications of this will be discussed in more detail in the last section of this paper.

---

40 As above 551.
44 “Social spending squeezes budget” Mail & Guardian 3 September 2004, 6.
4. Why is Access to Social Assistance a Human Rights Issue?

The recognition of access to social assistance as a human rights issue is not universally accepted. Socio-economic rights, including amongst others, a right of access to social assistance, housing, education and health, are considered “second generation rights” in the traditional human rights discourse and are not widely accepted due to various reasons, including the difficulty in justiciability of such rights. However, social assistance is a human rights issue that is related to the preservation of human dignity. When people live in poverty, which is often described as the greatest denial of human rights, they cannot live with human dignity, nor are they able to access other human rights such as education, health, water, food and other civil and political rights.45

In South Africa, however, socio-economic rights are clearly embedded in the Constitution, and have been held to be justiciable. The right to have access to social assistance is guaranteed in section 27(1)(c) of the Constitution, but is subject to progressive realisation within the available resources of the state.46 In the case of Khosa and others v Minister of Social Welfare,47 the Constitutional Court was asked to examine the constitutionality of the exclusion of non-citizen permanent residents from the social assistance scheme. It was recognised that the right to social assistance was intertwined with the right to life, dignity and equality.48 Mokgoro J stated the following:49

   The right of access to social security, including social assistance, for those unable to support themselves and their dependants is entrenched because as a society we value human beings and want to ensure that people are afforded their basic needs. A society must seek to ensure that the basic necessities of life are accessible to all if it is to be a society in which human dignity, freedom and equality are foundational.

   Thus, the links between social assistance and human rights are clear.

   It is also clear that those who live in poverty are vulnerable to other human rights abuses, and also have increased vulnerability to HIV/AIDS. Poverty increases people’s vulnerability to HIV/AIDS as people may engage in risky sexual behaviour for survival. For example, women and children may need to engage in “transactional sex” in order to obtain cash or goods for survival. In addition, women who are economically dependent on men may be unable to negotiate condom use with their partners. Poor women and children living in crowded homes are more likely to be sexually exploited or assaulted. All of this leads to an increased risk of contracting HIV.

   In addition to poverty leading to an increased risk of HIV, HIV compounds existing poverty. Women are traditionally the caregivers and need to take care of those in the household who are sick, often the breadwinners. Children, most often girls, may need to drop out of school to care for their parents who are ill, or to care for younger siblings when their parents are too ill to do so. Studies have shown that households affected by HIV/AIDS are significantly poorer than non-affected households.50
5. Issues Relating to Disability Grants at Local Level

The purpose of the Tswelopele research study of the Centre for the Study of AIDS was to examine whether the rights-based approach to HIV/AIDS, which has been formulated in various documents, policies and campaigns, has had an impact at local level. 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.

Throughout the study, the issue of access to social assistance came through very clearly. Socio-economic issues were raised by both PLHAs and non-PLHAs. The findings illustrated the complexity of socio-economic issues: the reliance on social assistance to keep people out of absolute poverty, the construction of stereotypes and stigma, and the process of discrimination against PLHAs.

The unemployment rates for the sample community of Hammanskraal is high, with many people being unemployed and with low levels of education. The high levels of poverty and unemployment were identified in focus groups and in key informant interviews as major problems in the area. The high level of unemployment was seen to be the cause of many social problems, such as drug and alcohol abuse, crime, domestic violence, rape, prostitution, and learners withdrawing from school and/or being unable to continue with their studies past Grade 12, due to an inability to pay fees. Social grants were seen to be vital, and many people were receiving one form of grant or another, most often their only means of monthly income and necessary for survival. Thus, the access to a steady monthly income was identified as an important issue and one that people felt strongly about.

The study highlighted a variety of issues surrounding application for and access to the disability grants for PLHAs, including issues regarding eligibility, violations of human dignity, perceptions of welfare fraud and abuse, and links to privacy and disclosure. These will be discussed in more detail below.

5.1 Issues of eligibility

The findings of the study highlighted various issues with respect to eligibility for disability grants. Firstly, there was a lack of understanding of the legislative and policy guidelines by people in the community, which was influenced by the differentiation in the standards of eligibility applied at different clinics and hospitals and even by different health care workers in the same institution. This differentiation in turn was illustrative of a number of attitudes regarding the purpose of the disability grant and the position and prospects of PLHAs amongst health care workers and PLHAs. Finally, the differing standards also had important implications for the behaviour of people with respect to HIV/AIDS.

Despite the clear definition to the contrary, PLHAs in Hammanskraal became eligible for a disability grant

51 I will be using the research conducted in Hammanskraal as the basis for this discussion, with the recognition that the findings cannot be generalised to all of South Africa due to a lack of random sampling and small sample size. However, the research site provided a good example of a peri-urban community in South Africa, and the findings do have indicative value.


53 For more information on the demographic situation of Hammanskraal, refer to the situation analysis conducted of the area as part of the study. Available from the Centre for the Study of AIDS.

54 Such as the foster care grant, child support grant, or disability grant. See Appendix 2 of the original Tswelopele Report for information on sources of monthly income of interviewees.

55 The issue came up in all four focus groups with PLHAs, all three focus groups with health care workers, all three focus groups with social clubs and with the local government councillors. The issue did not arise in the focus groups with the police and with the youth. Similarly, the issue arose, but most often in the context of orphans and foster care grants, with the key informant interviews.
immediately upon testing positive, even if they did not show any symptoms of AIDS or suffered from opportunistic infections. This means that the district health care system did not take into consideration CD4 count, used by the national department as a measure of physical impairment,\(^6\) when determining whether or not a person living with HIV was eligible for a disability grant.

This was confirmed in an interview with an administrator at the North West Province Department of Social Welfare. The use of the CD4 count as a measure of impairment had not yet been implemented in the area, due partly to the fact that the machine to measure CD4 was costly and there was no machine in the area. However, the Department was investigating the matter and policy, in line with the policy of the national department, was expected.\(^5\)

Until such time as standardisation through the use of CD4 is implemented, doctors were left with a great deal of discretion to determine whether a person would be eligible for the grant. The following excerpt from the interviews conducted during the research illustrated the differentiation amongst health care workers on eligibility for disability grants:\(^5\)

Female 3: That doctor, immediately, after she picked up your file and see that you are infected, she will tell you bad things. When she was supposed to fill up forms for me, she put me on a scale and said, “No, your weight allows you to live normal. You are not going to get a grant. I can’t give you pension, you are still strong.”

Interviewer: Where? In Jubilee?\(^5\)

Female 3: Yes. I said to her, yes I know but I was told that if you are in this state, you qualify regardless of whether you are strong or not. She said, no, no, no! ... The other doctor...I said I want to see Dr—... and that doctor said, “What are you going to ask?” and I told him and he said “No, there is nothing like that. We have heard that she refuses to fill up forms” and he filled them up. ...

The idea that a CD4 count of less than 200 should be used as a benchmark for purposes of determining physical impairment to access grants was highlighted as problematic from a number of different perspectives. Nursing sisters acknowledged that the grants were to be provided to people with CD4 counts of less than 200, but thought that it was useless to give people grants at that time since they were dying.\(^6\)

Interviewer: But what do you think? What do you think they should be given a grant if they do get infected?

Female 1: No, I think when the person is ...

Female 2: They must know they can live for 10 years.

Female 1: I think that only the doctor can say this person is eligible for grant or not because they will check the CD4. They doctor must assess like before and he’s the one who will know this is suitable for grant CD4 less than 200. One is dying, when is he going to enjoy the grant?

Female 2: It is a funeral ... so you are dying and then they give you the grant.

The period of time between applying and receiving the grant was also seen as a problem: the point was made that a person with a CD4 count below 200 would probably be dead by the time he/she received the grant due to the current backlog in processing the grant of three to six months. Finally, a clinic doctor described the ethical dilemma with respect to the eligibility of grants. He suggested that, in the context of the high unemployment

---

56 A PLHA would be automatically eligible if his or her CD4 was below 200, as this indicates the final stages in full-blown AIDS.
57 Key Informant interview 12.
58 FG4 (PLHAs).
59 Jubilee Hospital is the public hospital in the area.
60 FG7 (Health care workers).
in the community and the backlogs in accessing grants, and to ensure that PLHAs who were still healthy had access to food to stay healthy, he had little problem with completing the forms of people living with HIV, even if they did not technically fall within the definition of disability.61

The belief that one is eligible for the grant as soon as one tests positive seems to have led to interesting behavioural changes amongst potential recipients, which in turn illustrated attitudes about HIV/AIDS and poverty amongst poor people. First, in the belief that they will be eligible for the grant as soon as they test positive many people came forward to be tested, with the express purpose of gaining access to the grant. In addition, a number of participants in the study indicated that they had heard of people who, through unprotected sex, deliberately wanted to infect themselves with the aim of getting access to the grant:62

Female 5: Yes people are coming because I remember last time in the funeral, people were saying “hey --- we are coming on Monday for your help” and I said “no I don’t work there”... So people just want to come for grants, they don’t want to know their status. They just want to come there and have the grants; they just want to have money, the grants.

Male 1: And the other problem that encourage this is, the one of unprotected sex, is the very grant that they are going to have. It leads to one to have sex because grants are available.

Female 2: Another problem was that ... it is just a rumour that I heard, I haven’t met any person doing that. But people are saying that people insist on their tests to be positive. If you say that their tests are negative, they will kill you for that. They want to be positive so that they can apply for a grant. This is just a rumour I heard. I haven’t met any person doing that.

5.2 Violation of human dignity

Various issues emerged in the groups relating to social assistance, and these were often associated with the violation of human dignity.

Receiving a monthly income was for PLHAs a very important means to remain self-sufficient and to thus maintain their dignity. An illustrative exchange in the focus group follows:63

Female 6: I hope God helps me with my social grant. I have no one on my side.
Interviewer: You haven’t received your social grant?
Female 6: No.
Female 3: You must check next month.
Female 6: You know after receiving my money, you know I will stay in my house and eat whatever I like. You know, I will erect a stop [sign] and [stop] nonsense and when you came I will say, “Can I help you?” When you say “I’m asking for sugar”, I will say it’s finished. And I won’t open. I just want to be alone with my children, if they want to go and play they will go and play. Because relatives (whispers). I just want the government to give me money and die with a full stomach.

This need to be self-sufficient was closely related to financial abuse by families and friends. Family members were seen to be the worst violators of human rights of those with HIV or AIDS. For example:

Female 1: ... that is why the one who is not infected will not come to see me. He will only come after I have received my social grant.64

Female 5: Like where I stay, there is this guy who is suffering from this disease, when he wants to

61  Key Informant Interview 15 (Clinic doctor).
62  FG5 (Health care workers).
63  FG3 (PLHAs).
64  Righting Stigma: Social Assistance
relieve himself he doesn’t use the family toilet. They don’t want him to use their toilet. He is using the sewage on the street. They don’t want him to use their toilet.

Female 4: His own family?
Female 5: Yes.
Female 6: You know when you are sick ...
Female 5: His family! You know he has sisters, and a mother. They all don’t want him. And now he received his social grant, now they just throw parties. They bought alcohol with his money.
Female 7: Does he agree?
Female 5: That person is very sick, he is very sick.
Interviewer: He can’t refuse ...
Female 5: Yes, he is very sick, there is nothing that he can do.65

Female 2: [People say] “You are also sick, why don’t you apply?” You want your zombies to come and steal my R700!66

Grants were also used to identify and stigmatise those who were presumed to be HIV positive by the community. This clearly impacted on privacy, confidentiality and human dignity as the process of stigmatisation with all the labelling, distancing, gossiping, shaming and blaming was set in motion:67

Female 3: And it’s tough when someone sees you in a queue and then asks you like “How! You are receiving a grant?” and then when they see you next time they will ask you, “are you still receiving a grant, have you received your grant?”
The other one will hold her waist to confirm if it is really you. So if you are rude, you will tell a person “are you surprised to see me here? Everyone comes here, what do you want here? Why don’t I ask you anything?”
Male 1: The other thing that the person who are working there will look at your age and say, “why are you receiving a grant so quickly?”
Female 4: “Why are you receiving a grant for?”
Interviewer: They ask you such questions?
Female 2: Yes. The very same people who will give you money.
Male 1: Your slip will show your ID number ... so they are surprised ...
Female 2: They are not surprised, they know ...
Female 1: When you come clean, they will give you an attitude. When they undermine you, they will ask you questions. And then when he sees that you are not approachable ... you see when she comes this way I pull funny faces ...
Female 2: They say we finish government money (giggles) ... you know, I tell myself that, whether it is my next door neighbour or whoever, I don’t get the money that I receive from her house and I don’t get it from her husband’s salary. I get the money that I receive from the government and no one will ask me about my money because the government gives it to me. And it was not my intention to get this grant ...

It was clear that community members used the receipt of a grant as a means to identify that a person was HIV positive. If someone said that he or she had TB, but was at the same time receiving a grant, it was assumed that he or she was also HIV positive, and this matter soon become an issue of gossip for the community, with the accompanying destructive process of stigmatisation.68

5.3 Perceptions of welfare fraud and abuse

The male and female social clubs complained about welfare fraud. They had the perception that those who were not entitled to grants were receiving them, and
that the grants were being used to “purchase furniture” rather than to buy food. People from the female and male clubs had heard stories of people bribing doctors to fill out the forms:69

Female 1: We have realised that one thing about the grant – we assume that you are going to buy healthy food, what and what, but they start opening accounts at furniture shops and you find that this person is getting a grant but doesn’t feed, because she has decided to buy a bedroom set. They are not using the money for what we assumed that the money should be used for. Then if you are sick, you cannot even think of buying the bedroom set!70

Female 2: And there are some doctors who accept bribes like R500 so that he can write me a letter that says I’m HIV positive and to find that a person who is really in need of a grant cannot get it because she has to follow a long procedure.

Female 3: And you find that a real positive person dies without getting that grant but you on the other hand will wait until the money comes even if you can wait up to seven months because you are negative and strong.

Interviewer: Generally, is money more important than our health?

Male 2: In this community?

Female 1: Yes, money sold Jesus.

This belief that welfare abuse was being committed was multi-faceted, related to notions of “deserving” and “undeserving”. Since HIV/AIDS is sexually transmitted, there is clearly stigmatisation of those who have been infected. In fact, the belief that only sexually promiscuous people were infected came out very clearly in the research study. This separation of “us” from “them” may be a defence mechanism, but in any case creates categories that are so prevalent in issues surrounding welfare, that of deserving and undeserving recipients.

In addition, the belief in welfare fraud could be related to lack of information on the progression of HIV to AIDS. There was a fixation on physical appearance, for example whether someone was losing weight, was fat or skinny, was losing hair, or had pimples. People were concerned that those who appeared healthy were accessing disability grants. This was seen to be fraud because they were clearly not ill, related to the understanding of HIV/AIDS as being a disease that ravages people and makes them appear weak and thin. This in turn was related to the fact that many people who were living with HIV or AIDS did not disclose until they are very ill; thus the community only sees people who are terminal and this is their understanding of what it means to have HIV or AIDS. This comes back to issues of stigmatisation, of people not feeling comfortable to disclose and live openly, due to the fear (real or perceived) of being stigmatised, ostracised and isolated from the community.

Finally, the ideas of welfare fraud may be based simply on jealousy – in a community where unemployment is rife, and access to services is limited, people may just be jealous of others who have access to, in their view, a substantial sum of money every month. This jealousy, along with the lack of understanding of progression of HIV to AIDS, may lead to accusations of welfare fraud. In other words, economic imperatives take precedence over social imperatives in an environment of abject poverty, which subsequently leads to the perceptions already discussed.

The belief that welfare fraud was taking place, that people were getting access to disability grants and did not deserve to do so, had implications for other human rights such as privacy and disclosure, and informed consent and testing.

69  FG9 (Social club (Female)).
70  Feedback Session 4 (General feedback session).
5.4 Privacy and disclosure

The history of privacy and disclosure in relation to the AIDS pandemic is well documented and will not be repeated here, but it is clear that people recognise the importance of the values of privacy and disclosure. The importance of being able to decide when, to whom and how to tell people of one’s status has been clearly accepted and disclosure without one’s consent is recognised as a serious human rights violation.

However, in the research study, privacy and disclosure fell away in relation to perceived welfare abuse: people getting grants when they should not be receiving them. The method suggested to combat welfare fraud was to force PLHAs to undergo another HIV test, or another examination with a different doctor. These were justified to achieve the greater good of prevention of welfare abuse. This in turn related to informed consent and HIV testing.

5.5 Informed consent and HIV testing

In order to prevent welfare abuse, according to some of those interviewed, people should be tested and re-tested, even if it were without their consent.

Female 3: You know since there is too much crime in terms of grants, I was suggesting that if I go for tests and I find that I’m positive, and start receiving a social grant – I was suggesting that if you would still be alive after seven years, we must all for a re-test.

Group: Yes.

Interviewer: Can’t you bribe the doctor again?

Female 3: I think they must not go to the same doctor, maybe make use of the hospital or something like that. Or they must just call a meeting of all PWAs and when they arrive there, then they tell them it’s time for a re-test and no one should leave the meeting.

Female 2: They must take them to the stadium and lock the gates.

Thus, informed consent falls away in the pursuit of justice related to welfare fraud.

6. Current Issues that Require Further Research and Investigation

There are various other issues that arise from the research and from the current state of the disability grant in South Africa that need consideration. Some of these will be discussed briefly here.

6.1 Intentional infection to access disability grants?

One of the findings of the Tswelopele research study suggested that there was at least a perception that young people were engaging in risky sexual behaviour to fall pregnant in order to access child support grants. Health care workers complained.

Female 1: But most of the young ones, when you ask them about this pregnancy thing, they usually tell you that they want these grants ...

Interviewer: So do you think there are people who get deliberately; you know get infected by HIV, for the sake of the social grants?

Female 1: Yes, for the sake of the grants.

71 The importance of privacy and a choice for disclosure was clearly articulated by both PLHAs and non-PLHAs in the research. See ch 1 para 4.4.1 for more information on privacy and disclosure.

72 See, for example, the ethical guidelines on disclosure that guide health care professionals on when disclosure is acceptable. There have been several cases brought against doctors for disclosure without consent.

73 FG9 (Social club (Female)).

74 FG7 (Health care workers).
The issue of becoming intentionally HIV positive in order to access the disability grant was also raised, and needs to be highlighted as a potential issue. Will we be faced with a situation of desperate people who believe that they will get a disability grant if they test positive, engaging in risky or intentional behaviour in order to test positive? As ARV treatment becomes more readily available at public hospitals, the same desperate people may become positive and then go on treatment to prolong their lives. While there is little evidence to suggest that people are engaging in high-risk behaviour intentionally to become infected, this possibility cannot be dismissed outright.

### 6.2 A government re-evaluation of the definition of disability?

Early in the year, the Minister of Social Development expressed his concern about disability grant fraud, which was seen to be on the increase. He indicated, "This fraud is partly due to the inability to distinguish clearly between people who are disabled and people with chronic diseases. The disability grant is not intended to provide relief from chronic diseases". This sentiment has been echoed by the Treasury, which expressed a concern with the doubling of the disability grant payments from 2000/01 to 2003/04. The head of the Treasury's intergovernmental fiscal relations has stated: "We think there has been a considerable amount of abuse, which we are looking into". The government claims to be losing an estimated R1,5 billion a year to fraud committed through social grants.

On 26 October 2004, the Minister of Finance tabled the Medium-Term Budget Policy Statement, which outlined the choices that government has made about the sequencing of reforms and priorities for the period ahead. The Minister stated:

> We need to acknowledge that our social security net is under severe strain. Rapid growth in disability and foster care grant applications indicate both rising income support needs and apparent deficiencies in administrative systems. A sustainable social security system must balance bringing in everyone who is entitled to grants and keeping out everyone who is not entitled to them.

The Department of Social Development and the National Treasury have subsequently commissioned a study to examine the increase in disability grants, the results of which are expected shortly. While the study is being undertaken, there have already been indications that the government is turning its attention to the definition of disability, especially in relation to the eligibility of the disability grants. This required reform to put "in place steps to reduce the number of grants going to people who do not warrant them. These include a clear definition of disability and tightening procedures for other grants".

---

75 See, for example, *Risking HIV to access grant*, IRIN News Plus, available at www.plusnews.org/4D52Report.asp?ReportID=3296. (Accessed 15 June 2004. This article is about a young woman, Thato, who admitted she was thinking of contracting HIV to access a disability grant. She indicated that she had ten 'boyfriends' with whom she slept for money. She was supporting two nieces, her own child and a grand-mother who suffered from diabetes on the money she made by what she said was being a prostitute in disguise.


77 "Social spending squeezes budget" *Mail & Guardian*, 3 September 2004, 6.


79 [Minister of Finance Trevor Manuel, Address to the National Assembly on the tabling of the Medium Term Policy Statement, the Adjustments Appropriation Bill and the Revenue Laws Amendment Bill, 26 October 2004.](http://allafrica.com/stories/printable/200410280612.html?URL=//thenews/newsdesk/L26607908.htm)


82 [Minister of Finance Trevor Manuel, Address to the National Assembly on the tabling of the Medium Term Policy Statement, the Adjustments Appropriation Bill and the Revenue Laws Amendment Bill, 26 October 2004. The new social security agency will take over the administration and management of the social grants but in the interim the provinces will continue to administer the grants. This nationalisation will, it is hoped, deal with the current deficiencies in the system.](http://allafrica.com/stories/printable/200410280612.html?URL=//thenews/newsdesk/L26607908.htm)
Government has subsequently defined disability as a “moderate to severe limitation in functioning [activity] or participation restriction that is permanent. Disabilities are normally classified as physical, sensory, communication, intellectual and mental. The activity/functional limitation of participation restriction needs to exist after correction or control of impairment”. The Minister of Health has also commented that the definition required a careful assessment of the implications for the assessment of disability and the granting of temporary disability benefits.

Further this definition brings into question the issue of ARVs, namely will PLHAs who are ill and receiving disability grants be scared of losing their grants if they qualify and take ARVs? Clearly, this impacts on their ability to access health care and treatment, and may again lead to premature suffering and death, and spread of the disease as people are unwilling to receive treatment, even if it is available.

6.3 BIG – Dead in the water?

The Basic Income Grant (BIG) was a proposed R100 per person per household every month. Those that did not qualify for BIG would be responsible to repay the money through taxes. The system was meant to address the administrative and other challenges of the grants system (that is, children not having access to birth certificates or ID books, people not having knowledge about how to apply for social assistance, etc.).

The government never indicated a serious willingness to consider BIG as a means of ensuring that people have access to social assistance. While submissions were made to the Portfolio Committee on the report and recommendations of the Taylor Committee and various recommendations were made about the usefulness of BIG to combat poverty and HIV/AIDS, it would appear that BIG will never be a reality, especially in light of the current focus on welfare abuse, and those “deserving” and “undeserving” of assistance.

7. Conclusion

The purpose of this paper was to further explore the South African social assistance system, specifically with reference to PLHAs, using the Tswelopele research study as an example of a “typical” peri-urban setting. What is clear is that access to social assistance is related to many other human rights, and a violation of the right to social assistance has a major impact.

For PLHAs, access to social assistance relates to the threshold level to access the disability grant. While the law is clear on when a PLHA can have access to a disability grant, in practice this is not always followed. This raises several issues that include, amongst others, the definition of disability, impact on human dignity, stigmatisation, and welfare fraud. Many of these issues have been highlighted, with no clear answers, as those that will become more relevant as time goes on and will need to be addressed in the broader context of HIV/AIDS and human rights.

---

84 Ibid.
85 This concern was shared by IDASA, in a submission made to the Social Development Portfolio Committee on the Taylor Committee report, on 9 June 2003. IDASA recommended clear guidelines regarding grant eligibility while receiving ARVs.
86 See concerns raised about social welfare spending in the Mid-Term Policy Statement. See also “More grants, No BIG”, Mail & Guardian, 3 September 2004, p6. In an interview, the Deputy Minister of Finance stated that: “I don’t think that at this point the BIG will feature as one of the mechanisms to deal with poverty and vulnerability”.

Righting Stigma: Social Assistance
CHAPTER 6

Promoting the right to health care services for people living with HIV/AIDS in rural and peri-urban communities

Jennifer Joni*
Private consultant on HIV/AIDS

* E-mail jenjoni@hotmail.com.
1. Introduction

Since the first discovery of HIV/AIDS, governments have made strides in mitigating its effects among those affected. Even though innovative ways to address the scourge of the epidemic have been discovered, these have unfortunately not trickled down to the neediest individuals situated in poor-resourced countries where HIV/AIDS is concentrated. People in poor countries are still battling with the burden of disease and have not benefited from scientific discoveries that are responsible for, among other things, the reduction of the spread of the disease, prolonging the life of those already infected and prevention of mother-to-child transmission of HIV. Compounding the problem of access is the stigma attached to HIV infection and discrimination against individuals affected by HIV/AIDS. On a daily basis, people living with HIV/AIDS (PLHAs) are ostracised by their communities, refused employment and denied social security benefits and health care services. The list of human rights violations against PLHAs is endless.

In communities most affected by HIV/AIDS young people die prematurely because of lack of access to essential amenities, such as adequate housing, food, clean water, sanitation and health care services. In most instances, lack of access to services such as health care may be attributed to a lack of information and education, as well as fear of discrimination by the community and health care providers. In the South African context this is so despite the government’s constitutional imperative to ensure that every South African has access to socio-economic rights. Empowering people with the necessary skills and knowledge and promoting an enabling human rights environment is essential to ensure that international “best practices” in respect of HIV-related stigma and discrimination benefits all, especially rural communities affected by HIV/AIDS.

The first part of this chapter examines health systems delivery of HIV/AIDS related services in the public sector. The social and economic conditions of rural communities and how they impact on the lives of PLHAs are looked at to determine how they play a role in determining people’s vulnerability to HIV infection. The second part looks at the nature of stigma and discrimination in the delivery of health services within the Hammanskraal community. The part highlights the extent of stigma and discrimination suffered by individuals living with HIV/AIDS who access health care services and how the community is coping with such discrimination. This demonstrates the impact of such discrimination on the lives of individuals affected by HIV/AIDS. The third part examines the intersection between human rights, HIV/AIDS and the right to health-care services. In this regard, international, regional and national (the South African constitutional framework) human rights instruments are examined. This is intended to throw light on how these human rights provisions can be used to promote the rights of PLHAs in poor-resourced settings. The last part looks at how human rights can be used to advance an argument for the promotion of better access to health care information and services and in the long run, the eradication of poverty. In conclusion, recommendations are made on how access to health services by PLHAs can be improved.

2. Health Systems Delivery in South Africa

Socio-economic conditions usually dictate the fate of individuals within a society. In many instances, people who live in dire poverty are usually the ones disproportionately affected by HIV/AIDS. This part examines the social and economic circumstances to determine their impact on the lives of the poor, especially in the context

---

1 See secs 26 and 27 of the Constitution of South Africa, Act 108 of 1996.
of HIV/AIDS. A statistical analysis is undertaken to measure the impact of HIV/AIDS in the general population. These observations are accompanied by an examination of responses by government, non-governmental organisations and AIDS service organisations to HIV/AIDS and the impact of such responses on the lives of those most affected by HIV/AIDS.

2.1 Overview: The position of people affected by HIV/AIDS in the Hammanskraal and Temba area

Apartheid has left a legacy of severe racial disparities in most spheres of South African life. The harsh reality of this legacy is seen in the different levels of education among the different racial groups, as well as between men and women. More women than men have no education at all and fewer women than men graduate from high school. Among African women there is a low percentage of those with post-high school qualifications. Literacy levels often determine a person's access to services, especially employment. Employment in turn facilitates access to basic services because when an individual is in employment they can purchase services.

Post-apartheid efforts have reduced some disparities in education. According to the 2001 census, almost equal numbers of women and men attend universities (143 000 men and 145 000 women) and colleges (113 000 men and 119 000 women). Technical colleges, which focus on apprenticeships, are still, however, dominated by men.

Even though the position of people has generally improved, the lives of people who reside in areas previously described as independent and self-governing territories has remained unchanged. Communities such as those in Hammanskraal and Temba are still battling with the consequences of apartheid such as lack of education and poverty, which makes them more vulnerable to HIV infection.

Social and economic conditions of communities in rural Hammanskraal and Temba

The situation of the Hammanskraal community is no different from that of millions of South Africans who live in dire poverty. Rural communities are plagued by unemployment and poverty. Young school leavers find themselves without jobs unless they venture to big cities in search of a better life. Most of the respondents in the current research highlighted the fact that the biggest problem facing their community is poverty and unemployment. Both the focus groups and the interviews with key informants reveal that unemployment is one of the factors that make them vulnerable to HIV infection.

Patterns of access to health care services

Access to health care services is often determined by social and economic status. Individuals who are in employment often access health services through the private health care system while those who are poor and unemployed are provided for by the government through the public health care system.
health system. Stark differences exist between these two systems, with better and sustainable services obtainable in the private health system. In the Hammanskraal and Temba area the community accesses services through one hospital, 26 primary health care institutions and two mobile clinics. Service provision through these institutions is said to be inadequate and does not meet the needs of the community, especially those affected by HIV/AIDS.8

2.2 HIV/AIDS in South Africa

General prevalence

By 2004, more than 40 million people in the world were infected with HIV/AIDS, about 28,4 million of whom lived in sub-Saharan Africa.9 Southern Africa, in particular, has the highest rate of HIV infection. In South Africa alone, over 5 million people are infected.10

Research conducted by South Africa’s Department of Health (DOH) and other agencies confirm the international statistics. According to the annual national sentinel survey conducted by the DOH, infection rates have steadily increased since the survey was first conducted in 1990.11 The 1990 infection rate was 0.7%, by 2003 the sentinel survey revealed a prevalence rate of 27.9% (Figure 1),12 a more than threefold increase in the number of South Africans with HIV/AIDS in 13 years.

The survey conducted by the DOH has to a large extent been substantiated by research conducted by private agencies in South Africa. A report commissioned by loveLife shows an increase in HIV infections and an increase in AIDS-related death rates for people between the ages of 20 and 49 years.13 The infection rate ranges from 5% for those between the ages of 30 and 34, to 15% for those between the ages of 20 and 24. The increase in adult mortality rates is corroborated by a 2001 study by the Medical Research Council (MRC),14 which revealed that approximately 40% of deaths among people aged 15 to 49 were attributed to AIDS.15 The MRC findings emphasise the shift in mortality patterns, which they argue fit the established AIDS models.16

---

8 Note 2 above 12. Services provided at the clinics are voluntary testing and counselling and prevention of mother-to-child transmission of HIV/AIDS. At the time of the research it was not clear whether antiretroviral therapy would be provided by the one hospital in the areas.


10 As above at 77. This figure corresponds with the findings of the 2002 prevalence survey. The figure has however increased to 5,6 million infections in 2003.


12 As above, 6 (The graph here is reprinted from the DOH Sero-Prevalence Survey).


15 Ibid, at 6. The release of the MRC report attracted controversy, especially from the government. It was a rude awakening and confirmation of the truth that HIV and AIDS are killing people in South Africa. The government disputed these findings mainly because HIV is not a ‘notifiable’ disease in South Africa. That is, the figures might not be a true reflection of the state of affairs because there is no obligation to report on HIV/AIDS-related mortalities.

16 Ibid.
HIV prevalence in Gauteng and the North West Province

The 2003 antenatal survey, which is the fourteenth since the 1990 survey, provides a breakdown of prevalence according to provinces. The 5.6 million South Africans infected with HIV are fairly distributed among the provinces, although some provinces, especially ones with high population and poverty rates, have shown higher infection rates. Another contributing factor is migration. People who migrate to places where there are jobs make themselves more vulnerable to HIV infection. This is the case with poor people who migrate to big cities in search of a better life.

<table>
<thead>
<tr>
<th>Province</th>
<th>HIV prev (CI 95%) 2001</th>
<th>HIV prev (CI 95%) 2002</th>
<th>HIV prev (CI 95%) 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>KwaZulu-Natal</td>
<td>33.5 (30.6-36.4)</td>
<td>36.5 (33.8-39.2)</td>
<td>37.5 (35.2-39.8)</td>
</tr>
<tr>
<td>Mpumalanga</td>
<td>29.2 (25.6-32.8)</td>
<td>28.6 (25.3-31.8)</td>
<td>32.6 (28.5-36.6)</td>
</tr>
<tr>
<td>Free State</td>
<td>30.1 (26.5-33.7)</td>
<td>28.8 (26.3-31.2)</td>
<td>30.1 (26.9-33.3)</td>
</tr>
<tr>
<td>North West</td>
<td>25.2 (21.9-28.6)</td>
<td>26.2 (23.1-29.4)</td>
<td>29.9 (26.8-33.1)</td>
</tr>
<tr>
<td>Gauteng</td>
<td>29.8 (27.5-32.1)</td>
<td>31.6 (29.7-33.6)</td>
<td>29.6 (27.8-31.5)</td>
</tr>
<tr>
<td>Eastern Cape</td>
<td>21.7 (19.0-24.4)</td>
<td>23.6 (21.1-26.1)</td>
<td>27.1 (24.6-29.7)</td>
</tr>
<tr>
<td>Limpopo</td>
<td>14.5 (12.2-16.9)</td>
<td>15.6 (13.2-17.9)</td>
<td>17.5 (14.9-20.0)</td>
</tr>
<tr>
<td>Northern Cape</td>
<td>15.9 (10.1-21.6)</td>
<td>15.1 (11.7-18.6)</td>
<td>16.7 (11.9-21.5)</td>
</tr>
<tr>
<td>Western Cape</td>
<td>8.6 (5.8-11.5)</td>
<td>12.4 (8.8-15.9)</td>
<td>13.1 (8.5-17.7)</td>
</tr>
<tr>
<td>South Africa</td>
<td>24.8 (23.6-26.1)</td>
<td>26.5 (25.5-27.6)</td>
<td>27.9 (26.8-28.9)</td>
</tr>
</tbody>
</table>

Gauteng and North West Provinces, which are home to the respondents in the current research, have a prevalence of 29.6% and 29.9% respectively and they rank 4th and 5th when compared to other provinces. The report by the South African Human Rights Commission on socioeconomic rights (the ESR report) confirms that certain provinces have high infection rates than others. This is attributed “to high levels of poverty, especially in rural areas where 75% of the poor reside and where health care services are underdeveloped and often inaccessible”.

Vulnerability of rural communities to HIV/AIDS infection

Numerous factors are identified as determinants of vulnerability to HIV infection. Women for example are at high risk of infection because of the inferior position they hold in society. In many instances women cannot negotiate safer sex and sometimes they have to sell sex for money. Poverty also plays a role in determining who is infected because people are sometimes forced to put their lives at risk (of infection) if that would improve their living conditions. Exacerbating the problem of HIV infectivity are the high unemployment rates. Young people who

17 Note 11 above. This figure illustrates an increase from 5.3 million infections estimated for 2002. Of the people living with HIV in 2003 3.1 million are women, 2.4 million are men and 96 228 are infants.
18 As above, at 7 (The table here is reproduced from this source).
20 As above, at 43.
21 Some of the respondents interviewed for the Tswelopele Project highlighted how some people go for HIV testing with the hope that they would be positive and thus qualify for the social grants provided by the Department of Social Welfare to those who are infected with the virus. In extreme cases and out of desperation, people desire to be infected so that they are at least able to feed their families.
finish high school end up roaming the streets and behaving irresponsibly because they cannot find jobs.\(^{22}\)

The communities in Hammanskraal and Temba are not immune from factors that make people vulnerable to HIV infection. A large number of people in that community are poor, unemployed and have to travel long distances to access amenities vital for their livelihood.\(^{23}\) Those living in under-serviced areas are often at a disadvantaged position because lack of access to information and education means that they are unable to make choices about sex, prevention of infection and reproductive health. Thus, explanations for vulnerability to HIV infection ranges from one individual to another:\(^{24}\)

I think that the reason why it is mostly women is that women, especially married women, are obedient to their husbands. I have to listen to everything he says. Maybe he has three girlfriends apart from me. I’m the fourth one and I’m his wife. When he comes back from his girlfriends he will insist that we don’t use a condom. Maybe I am pregnant and I go to the doctor, when he checks me he will find that I’m HIV positive. So that is why we say most infected groups of people are women.

Most people have heard about the Constitution, but they have not made it part of their daily lives. People in authority, such as the police, officials in local government and health care workers, are also not well versed in how the use of the Constitution can improve the human rights of people within their community.\(^{25}\)

The role of government and civil society in assisting communities affected by HIV/AIDS

Government has at many levels attempted to address the devastating effects of the epidemic. This has been through the formation of institutions providing a platform to discuss HIV-related matters. A few of these institutions are the South African National AIDS Council (SANAC) headed by the Deputy President, and MINMEC, comprising of the Minister of Health, provincial ministers of health and provincial and local government AIDS councils. Although these are sometimes not regarded as key to addressing the problems directly faced by those living with HIV/AIDS, they have opened a dialogue on the subject.

Another positive step has been the formation of independent non-governmental organisations (NGOs) and community based organisations (CBOs). Both the NGOs and CBOs are critical for dealing with abuses of human rights of those affected by HIV/AIDS because they are the only accessible places where individuals subjected to discrimination can seek help. The services provided by such organisations are instrumental in a society that has many poor people who live below the poverty line and are therefore unable to protect themselves. While hard data on the number of NGOs that operate in South Africa is unavailable, one source estimates that there are approximately 50 000 NGOs and CBOs.\(^{26}\) From the early days of the epidemic, organisations focusing on HIV/AIDS were formed as a response to the novel issues that the epidemic brought to communities and society at large – stigma and discrimination. Ubiquitous organisations such as the National Association of People Living with HIV/AIDS (NAPWA), the Treatment Action Campaign (TAC), the AIDS Consortium and the AIDS Law Project, although regarded as national organisations, are not visible in

\(^{22}\) Note 7 above, especially interviews with focus groups.  
\(^{23}\) Ibid.  
\(^{24}\) See ch 1 above para 4.2.5.  
\(^{25}\) Note 7 above.  
\(^{26}\) Hurt, K and Budlender, D (eds) (2001) Money matters three: Women and government revenue. It should be noted that while many of these organisations may exist elsewhere, there is less than a handful that are operating within the Hammanskraal and Temba area. Note 1 above 62.
rural areas. Rural communities are often left to their own devices, without organisations that have the necessary capacity to assist in addressing their problems.\(^{27}\) Very few people in rural settings know about NGOs or any other organisation that can assist them with their HIV/AIDS-related problems.\(^{28}\)

### 2.3 Government’s response to health care needs

In 1994 the democratically elected government inherited a system plagued by disparities in the distribution of services. Distribution of resources, including basic amenities of life, was disproportionate and largely based on racial lines. A good example is access to health care services.

In South Africa, health services are provided by the public and private health care systems. The public health care system caters for about 80% of the population (mostly black) while 13% is catered for by the private sector.\(^{29}\)

A large proportion of health spending, in this case 80% of total spending in the public and private sectors, subsidises the private health care system. Only 20% of total health care expenditure is allocated to the public health care system. Although the public health-care system services the needs of the majority, the amount spent on the needs of this group is disproportionate to the number of people it caters for. The other reality is that the public health care system services the needs of the majority of South Africans who happen to be black and mostly unemployed. Ironically this translates to most health care resources not benefiting those they were supposed to benefit – the poor and disadvantaged people of South Africa.

The ESR Report suggests that gains have been made by government in as far as delivery of health care is concerned.\(^{30}\) This report also mentions that government programmes for the year under review (2002/2003) are “reasonable” in their inception but that there are gaps in as far as implementation is concerned.\(^{31}\)

#### Government policies and guidelines dealing with HIV/AIDS

Many government departments have developed strategies aimed at addressing and mitigating the effects of HIV/AIDS. The policies are indicative of a general commitment to the issues, and provide body and flesh to some of the ideals and principles that the broader legal framework does not adequately explain. In the context of HIV/AIDS, the guidelines have been instrumental in giving constructive direction on critical issues such as confidentiality, HIV testing, legal and human rights. Some of these guidelines also prescribe how stigma and discrimination can be dealt with in the provision of health care services, especially for vulnerable groups, such as people living with HIV/AIDS. Overall most of government policies promote a human rights-based approach that suggests how stigma and discrimination could be eradicated.

---

\(^{27}\) This refers to both governmental and non-governmental organisations. With regards to the former, existing local government structures do not have the necessary capacity and skills to assist community members, alternatively they lack interest as HIV/AIDS and human rights are not regarded as political enough to attract their attention. In as far as NGOs are concerned, a few of those that exist do not have the capacity (human and financial) to assist community members affected by HIV/AIDS. These sentiments have been confirmed by almost all the respondents who agreed that in their area there are no organisations that they can approach when their rights have been violated or for that matter to get information about their rights. The respondents further confirmed that one of the few known and available alternative where rights have been violated, is reporting the matter to the police – which in many instances has proved futile.

\(^{28}\) See ch. 1 above para 4.6. For those community members who know about the existence of NGOs, they feel that these organisations are only visible when there is a campaign on a particular issue. At the end of the campaign, they are not available to give guidance with regards to the problems they face in their daily lives.

\(^{29}\) Note 19 above 60. See also Heywood, M “Debunking the Conglomo talk” available at www.alp.org.za/rect/ri/rapps/misc/20011203_resdebunk.rtf (accessed 14 November 2004).

\(^{30}\) As above, xiv.

\(^{31}\) Ibid.
The Department of Health’s Strategic Plan for 2000-2005 (the Strategic Plan)\textsuperscript{32} was the first policy that became a building block in developing strategies for dealing with HIV/AIDS. The strategic plan outlines a human rights-based approach that must be followed in dealing with HIV/AIDS, which includes monitoring human rights abuses and developing enforcement mechanisms for redress.\textsuperscript{33} Another relevant policy document is the Operational plan for comprehensive HIV/AIDS care and treatment for South Africa (the Operational Plan),\textsuperscript{34} which was approved by Cabinet (in November 2003) as a framework that the Ministry of Health should develop and implement to ensure that PLHAs have access to prevention, care and support for HIV-related services.

**Delivery of HIV-related services in the public sector**

Service delivery in the public sector has been achieved despite inherent problems that surround an equitable distribution of services. In pursuance of its mandate set out in the Strategic Plan,\textsuperscript{35} the Operational Plan\textsuperscript{36} and various documents, national government has put in place numerous strategies aimed at mitigating the impact of HIV/AIDS among those affected. Among these programmes are: prevention-of-mother-to-child-transmission of HIV/AIDS (PMTCT), voluntary counselling and testing (VCT) and treatment of HIV/AIDS through antiretroviral therapy (ARV). Although it took a lot of convincing for some of the programmes to be implemented, most public health service points provide HIV-related services for the benefit of those who are poor and would otherwise have no access. The first of such programmes was the implementation of the PMTCT programme around May 2001.\textsuperscript{37} This was followed by the VCT programme and post-exposure prophylaxis (PEP) initially for health care workers (who sustained needle-stick injuries in the course of their duties) and later for rape survivors.

Other departments have also chipped in to come to the assistance of PLHAs. For example, the Department of Social Welfare provides social grants to those infected with HIV.\textsuperscript{38} However insignificant, the gesture has improved lives of many poor people who are affected and infected with HIV/AIDS. The amount received has enabled those infected to support themselves by buying nutritional food and supplements to ensure that they do not prematurely succumb to the debilitating effects of the disease.

3. **Stigma and Discrimination in the Delivery of Health Care Services**

Stigma and discrimination directed at those found to be living with HIV/AIDS is still prevalent within most communities. This treatment of PLHAs has been responsible

\textsuperscript{33} As above, 23.
\textsuperscript{34} The Operational Plan, as it is affectionately known, has a long history. The Plan was developed by the Treatment Action Campaign (TAC) around 2001 as a model that government could adopt to increase access to HIV treatment in the public sector. When government refused, TAC presented the Plan to the National Economic Development and Labour Council (NEDLAC) for discussion and deliberation by business, labour, government and civil society. Shortly after the completion of the NEDLAC process Cabinet issued a statement on 19 August 2003 instructing the Minister of Health to develop a treatment plan. The Minister of Health published the plan, which basically documents the strategies debated at NEDLAC in 2002. The document can be viewed at www.gov.za/issues/hivcareplan19nov03.htm (accessed 18 October 2004).
\textsuperscript{35} Note 30 above.
\textsuperscript{36} Note 32 above.
\textsuperscript{37} The PMTCT programme was implemented as a pilot programme in 2000 at designated sites throughout the provinces. The limited nature of such provision led to the case brought by the TAC against the Minister of Health in August 2001. The details of that case are discussed in detail below.
\textsuperscript{38} See ch 1 above para 4.5.1. The criteria used by the Department in providing social benefits for those infected with HIV/AIDS is not clear. Different provinces have different criteria that they use to determine whether an individual qualifies for the said grant. Respondents in the Tswelopele Project indicated that they become entitled to the grant by virtue of being infected with HIV.
for driving millions away from services that are necessary for their well-being. Although stigma and discrimination vary from one person to another and one community to another, the phenomenon is still rife and far from over. This part looks at the forms of stigma and discrimination directed at those living with HIV/AIDS when accessing health-related services. The part also looks at how individuals protect themselves from discriminatory practices.

3.1 Delivery of HIV-related services in rural Hammanskraal and Temba

The Tswelopele research has illustrated that poverty and deprivation has made a number of people vulnerable to infections such as HIV and AIDS. What this has meant for most people is that ways have to be found to determine the nature of HIV and AIDS discrimination and measures that can be used to eliminate it. Many quarters have conducted research on stigma and discrimination but all those endeavours have not produced the desired results. The conclusion that can be drawn is that the messages that have been used so far are not communicated in a language and through ways that people sufficiently understand.

On the exact nature of stigma and discrimination there are different opinions from the people interviewed in the Tswelopele research. Members of the focus groups interviewed were able to articulate what it means to be subjected to stigma and discrimination. Such views were expressed especially by people directly affected by HIV/AIDS, either because they were themselves infected or because they had family members who were infected. The sentiments of those who participated in the research are confirmed by Richter, who states that the “experience of discrimination is highly subjective” and that “no report can reproduce the feelings of fear, stigma and personal pain endured by people who have ascertained their HIV status and who have felt the terror, disapproval and arrogance of the prejudice of others.”

Information about what health care is provided in the public sector is very sketchy and in most instances contradictory. Health care workers (HCWs) who participated in the Project have their own account of what is provided, while the community has its own expectations. For instance, HCWs blame their inability to provide services on the pressure they work under and unrealistic expectations from the public. They also emphasise that health care facilities are understaffed, and that HCWs are affected psychologically by the calamitous nature of the epidemic. Although HCWs work under difficult conditions, much blame for the way they deal with patients can be placed on their ignorance and the fact that in most instances their training does not include management of HIV and AIDS.

Service delivery in rural areas has been marred by a lack of infrastructure, personnel and medicines. Most of the inadequacies of the health systems in these areas have been inherited from the past, where the administrators did not have the revenue to ensure adequate service delivery. There are accounts of services that are provided in rural areas, and these range from VCT, PMTCT to palliative care services. Ignorance, lack of understanding the importance of participation, and fear of stigma and discrimination has often led to a low uptake of these services and some of the programmes offered to PLHAs.

There are reports relating to numerous violations of human rights in the health care system. Unlawful disclosure of HIV status, HIV testing without informed consent and refusal to provide treatment are common complaints. Although this is denied by HCWs providing these services, community members insist that it happens on a daily basis.

39 See focus group interviews. The statements made by the majority of those interviewed confirm that people living with HIV/AIDS are indeed subjected to discrimination within their families and society at large. That is why most of the interviewees find solace at participating in focus groups run by hospices or community based social clubs.


41 Ch 1 above para 4.4.3.

42 Ch 1 above para 4.4.1.
3.2 Community’s response to discrimination and stigmatisation in the delivery of health-related goods and services

Because stigma and discrimination are a daily occurrence in the lives of people living with HIV/AIDS, people have often found ways of dealing with it. As most discrimination takes place in intimate relations or is perpetrated by people in authority, PLHAs have often been forced to deal with the situations in which they find themselves.

In response to discrimination meted out at those with HIV/AIDS by HCWs, communities have devised ways of coping. In the first instance, those affected by HIV/AIDS have resolved not to seek help from health care workers for fear of bad treatment and breach of confidentiality. Some of those affected have indicated that, instead of exposure to bad treatment and humiliation, they would rather be left at home to die. Second, affected individuals have decided not to inform their family members of their HIV status for fear of being ostracised.

The attitude displayed by most PLHAs is that of doom and gloom. Discrimination and stigmatisation of those living with HIV/AIDS have often led to a violation of PLHAs' rights to dignity, privacy and bodily integrity. As a result, PLHAs are discouraged from accessing health care services. This is seen, for example, in cases where people who are infected refuse to access essential services such as VCT and ARVs even where such services are readily available. PLHAs in dire need of information on treatment, nutrition and supplements and counselling, often opt for self-help methods like joining youth groups, stokvels or other community groups.

4. The Role of Human Rights in Eradicating Stigma and Discrimination in the Delivery of Health Care Services

Human rights law prescribes that everyone is entitled to human rights and that governments have an obligation to respect, protect and fulfil these rights. This part looks at how human rights can be used to ensure that those affected by HIV/AIDS are provided with the basic level of care in time of need. It examines human rights instruments that promote protection of rights of individuals affected by HIV/AIDS. It also looks at how international 'best practice' and the South African Constitutional framework have been developed and interpreted to advance and ensure the provision of the right to health care services to those affected by HIV/AIDS.

4.1 Human rights, HIV/AIDS and the right to health care services

The HIV epidemic has highlighted the link between the promotion and protection of human rights and the promotion and protection of health. In this regard a violation of human rights is likely to lead to the spread of the epidemic. People living with HIV/AIDS have a right to health, which has been described by the World Health Organization as a “state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.”

---

43 Ch 1 above para 4.3.2.
44 As demonstrated previously, fear of stigma and discrimination lead PLHAs to seek alternative methods of coping. They are reluctant to, for example, test and access information on how to prevent the further spread of HIV.
4.2 International ‘best practice’

International conventions

A number of international treaties promote the protection of socio-economic rights: the Universal Declaration of Human Rights (UDHR) (article 25),46 the International Covenant on Economic, Social and Cultural Rights (ICESCR) (article 12)47 and the African Charter on Human and Peoples’ Rights (ACHPR) (article 16).48 The ICESCR obliges states to “take steps ... to the maximum of its available resources, with the view to achieving progressively the full realisation of the right by all appropriate means, including particularly the adoption of legislative measures”.49 The protection of the right to health care services means that PLHAs should not be denied the right to the highest attainable standard of physical and mental health.

General comments and guidelines

Over the years international resolutions and recommendations have been developed to address HIV/AIDS, and define the rights contained in international conventions. Although not legally binding they represent international consensus about the rights of people living with HIV/AIDS.

In the context of HIV/AIDS the most relevant document is the Guidelines on HIV/AIDS and human rights that was developed in 1996. These guidelines provide a comprehensive, detailed and specific guidance on how human rights should be promoted and protected. Although not legally binding, they prescribe an internationally recognised standard that governments have to live up to. Guideline 6,52 which was revised in 2002, requires governments to

General Comment 14,50 which was issued by the Committee on Economic, Social and Cultural Rights, has defined the right to the highest attainable standard of health care prescribe in the Covenant on Economic, Social and Cultural Rights. The Committee has emphasised that the right to health care services is not confined to health care, but relates to a range of services that have to be provided to ensure that people are healthy. These are nutrition, housing, uncontaminated drinking water, sanitation, safe workplaces and a healthy environment. The right has also been defined to relate to “availability, accessibility and acceptability.”51 In the context of the current research it could be argued that government has an obligation to provide people with information that would enable them to make better choices about their lives, especially information that could assist them avoid HIV infection.

46 The Universal Declaration of Human Rights was adopted on 10 December 1948, its art 25 states that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control”.

47 The International Covenant on Economic, Social and Cultural Rights was adopted on 16 December 1966 and it came into effect on 3 January 1976. South Africa signed the Covenant on 3 October 1994 but it is not yet ratified. Art 12 provides the following:

“(1) The States Parties to the Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

(2) The steps to be taken by the State Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness” (emphasis added).

48 Article 16 of the African Charter states as follows:

“(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.

(2) State parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”

49 Note 46 above at art 2(1). In real terms this means that States are required to create a legal framework that would grant individuals rights and privileges that would enable them to pursue their rights.


51 Availability means that health conditions should exist, such as public health and health care facilities. Accessibility relates to services that should be accessible to the entire population. Acceptability means that the services should adhere to acceptable standards and ethics.

ensure access to prevention, treatment, care and support. This includes access to HIV antiretroviral and medicines, diagnostic and other related services. For the achievement of eradication of discrimination against PLHAs, human rights should be the main focus.

4.3 The South African constitutional framework and the content of the right to health care

The Constitutional framework, especially that of South Africa, has followed the standards as set out in international Covenants and guidelines. The Final Constitution, adopted in 1996, gave birth to a regime that entrenches fundamental freedoms. The Bill of Rights guarantees to all South Africans rights that are absent in most modern Constitutions – socio-economic rights. One of the most important among these rights in the context of HIV/AIDS is the right to health care services, read with the right to equality, the right to human dignity, and the right to life.

The analysis of the constitutional right to health care services

Provision of health care services as regulated by section 27 provides that government has to provide health care to those in need, to the best of its available resources. What this means, among others, is that the state cannot infringe the right to health care by implementing retrogressive measures in making the services available. This also means that the state should implement legislative measures to ensure the full realisation of this right. When dealing with the rights of people that the Constitution was intended to protect, the clause relating to provision of health care services should be seen within the milieu of the promises made in the preamble of the Constitution. The Constitution is adopted to “improve the quality of life of all citizens; and free the potential of each person”.

The first time the Courts were called upon to adjudicate on socio-economic rights, particularly the rights to health care services, was within the context of section 35(2)(e) which deals with the right of prisoners to medical treatment. In one of such cases the challenge was around provision of antiretroviral therapy to HIV-positive prisoners. The Courts noted that there is a difference between the provisions of sections 35(2)(e) and 27 (which is a general provision dealing with health care services) in that with the former provision, the fulfilment of the obligation by the State is not dependent upon availability of resources. Nevertheless, the Courts argued that in the particular circumstances what the State has to provide is “adequate medical treatment” which is different from “access to medical health care services.” Therefore what is guaranteed...
is not optimal medical care or the best medical care available but that which is adequate and determined according to what is provided to other citizens outside of prison.

An analysis of the rights protected in the Constitution illustrates that the socio-economic rights entrenched in the Constitution are not absolute. The progressive realisation of these rights is dependent upon the state's available resources. Be that as it may, the extent of the protection of the rights in the Bill of Rights has to be read in the context of section 7(2) of the Constitution, which requires the state to "respect, protect, promote, and fulfil the rights in the Bill of Rights". The state's duties to fulfil the rights entrenched in the Constitution has negative and positive dimensions. The former means that the state has to refrain from infringing people's rights, whilst the latter dimension means that the state has to take necessary steps to ensure the enjoyment of these rights.

The development of the jurisprudence on the right to health care

The significance of these rights became apparent in the face of the scourge of AIDS, reactions attributable to society's fear, ignorance and refusal to deal with HIV/AIDS. People affected by or living with HIV/AIDS found themselves confronted by stigma and discrimination. Some people were denied employment, discharged from their jobs, denied medical treatment, ostracized or even killed, solely because of their HIV-positive status.

Initially, it was not clear how the new constitutional rights were going to be interpreted, especially those that have a bearing on the livelihoods of many poor South Africans who rely on the generosity of the state for their health needs. The first case in which the parameters of the protection of the right to health care services were tested is Soobramoney. In that case the Constitutional Court was called upon to make a pronouncement on the right to health care services. The challenge was based on the right not to be refused emergency medical treatment as is provided in section 27(3). In this case the Court also dealt with rights contained in sections 27(1) and (2) – the right of access to health care services and the steps that the state is expected to take in fulfilling its obligations. The application was brought by an applicant who was refused dialysis treatment on the basis that the policy required the hospital to provide the treatment only to a limited number of patients. In the Court of first instance, where the matter was brought for the first time, the application was dismissed on the basis that rights is section 27 could be limited if such a limitation complied with the requirements of section 36 (the limitations clause). In dismissing the appeal, the Constitutional Court argued as follows.

---

61 In secs 26(2) and 27(2) a language that is identical has been used to emphasise that in realising their obligations the State must take reasonable measures depending on the availability of their resources. This relates to a practice by most employers wherein they conduct pre-employment testing for HIV, and if a job applicant tests positive for HIV, he/she is denied employment. In most of the cases, the employment decision is not based on any reliable medical evidence. For example, in a case ACM v Bulktrans JA498/00 (Unreported), a company transporting petroleum refused to employ ACM, who otherwise qualified for the job, because he tested HIV positive during the pre-employment screening process. The reason advanced was that it was the policy of the company not to employ HIV-positive individuals, as they tend to have neurological defects. The APL assisted ACM in challenging the company's policy, because there is no scientific basis for the blanket exclusion of everyone who has HIV, more especially where no battery tests have been conducted to determine whether the particular individual is prone to have the unwanted neurological defects. Like many similar cases, the matter was settled out of court with the respondent paying to ACM monetary settlement.

62 A good example is that of Gugu Dlamini of KwaZula Natal who, in December 1998, was stoned to death after she publicly announced her HIV status. This she did in December 1998 during an openness campaign organised by the Department of Health in KwaZulu-Natal. Her previous lovers are suspected of killing her because her public acknowledgement of her HIV status “shamed” her community. After a long delay in prosecuting her case, the prosecution dismissed the charges - because there was insufficient evidence to prosecute. For a detailed information on the events surrounding the case see http://www.aegis.com/news/ap/1998/AP981219.html; http://aidsinfnyc.org/hivplus/issue10/columns/perspective.html; http://hivnet.ch:8000/africa/af-aims/view/R7332; and http://dispatch.co.za/2001/01/12/southafrica/DLMINI.HTM (accessed 4 November 2004).

63 A good example is that of Gugu Dlamini of KwaZula Natal who, in December 1998, was stoned to death after she publicly announced her HIV status “shamed” her community. After a long delay in prosecuting her case, the prosecution dismissed the charges - because there was insufficient evidence to prosecute. For a detailed information on the events surrounding the case see http://www.aegis.com/news/ap/1998/AP981219.html; http://aidsinfnyc.org/hivplus/issue10/columns/perspective.html; http://hivnet.ch:8000/africa/af-aims/view/R7332; and http://dispatch.co.za/2001/01/12/southafrica/DLMINI.HTM (accessed 4 November 2004).

64 Soobramoney v Minister of Health, KwaZulu-Natal 1998 (1) SA 765 (CC), 1997 (12) BCLR 1696 (CC).

65 As above, para 28.
The appellant’s case must be seen in the context of the needs which the health services have to meet, for if the treatment has to be provided to the appellant it would also have to be provided to all other persons similarly placed. Although the renal clinic could be opened for longer hours, it would involve additional expense in having to pay the clinic personnel at overtime rates, or having to employ additional personnel working on a shift basis. It would also put a great strain on the existing dialysis machines which are already showing signs of wear. It is estimated that the cost to the State of treating one chronically ill patient by means of renal dialysis provided twice a week at a State hospital is approximately R60 000 per annum. If all the persons in South Africa who suffer from chronic renal failure were to be provided with dialysis treatment – many of them, as the appellant does, would require treatment three times a week – the cost of doing so would make substantial inroads into the health budget. And if this principle were to be applied to all patients claiming access to expensive medical treatment or expensive drugs, the health budget would have to be dramatically increased to the prejudice of other needs which the State has to meet.

The Court further argued that it was not its role to decide who should or should not receive medical attention or treatment. It resolved that medical practitioners were more qualified to decide on clinical grounds who would benefit most from the treatment. With regards to the rights in the bill of rights Sachs J commented as follows:

The provisions of the bill of rights should furthermore not be interpreted in a way which results in Courts feeling themselves unduly pressurised by the fear of gambling with the lives of claimants into ordering hospitals to furnish the most expensive and improbable procedures, thereby diverting scarce medical resources and prejudicing the claims of others.

Although Soobramoney illustrated the extent of the constitutionally protected right to health care, it did not give clear guidance on how the Constitutional Court or any court for that matter, would interpret the right to health care services for people living with HIV/AIDS who are at the receiving end of bad treatment. How, for example, would the Constitutional Court deal with HIV-related discrimination, which is not explicitly included in the list of prohibited grounds of discrimination in the Constitution’s equality provision? Even though the Constitution proscribes discrimination on the basis of a disability, it was difficult to predict whether the Court would accept that the definition of a disability includes HIV/AIDS.

The breadth of the protection afforded to people living with HIV/AIDS was tested for the first time in Hoffmann v South African Airways (SAA). The Court had to deter-
mine whether HIV-related discrimination which was allowed in the SAA policy fell within the purview of the Constitution. The Court was not shy to declare that the Constitution is there to protect all and to promote the democratic values enunciated in the founding provisions of the Constitution, among them, “human dignity, the achievement of equality and the advancement of human rights and freedoms.” 70 Justice Ngcobo, writing for the Court, stated emphatically that prejudice, stigmatisation and discrimination against PLHAs should not be tolerated: 71

... People who are living with HIV constitute a minority. Society has responded to their plight with intense prejudice. They have been subjected to systemic disadvantage and discrimination. They have been stigmatised and marginalised ... Society’s response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived them of the help they would otherwise have received ... In view of the prevailing prejudice against HIV positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity ...

The Constitutional Court also seized the opportunity to define the parameters of the protection to be afforded PLHAs with regards to provision of health care services in a case initially brought by the Treatment Action Campaign (TAC) against the Minister of Health. 72 At issue was the government’s failure or refusal to extend the provision of the drug Nevirapine, which reduces the incidence of mother-to-child transmission of HIV, throughout the country. The government had put in place mother-to-child transmission pilot programmes in some but not all the provinces for the provision of the drug. The Court was not hesitant to confirm its previous pronouncements on how society should treat HIV-related issues. It declared that the government’s programme did not meet its Constitutional obligation to take reasonable measures to realise the right to health care services under S 27 (1) and (2) of the Constitution. 73 The Court ordered the government to make Nevirapine available to all HIV-positive pregnant mothers where it is medically indicated and where public hospitals have capacity to provide the treatment. It also ordered the government to implement a plan that would ensure the effectiveness of the programme.

The judgment illustrates that treatment of HIV/AIDS is urgent and requires an urgent response. What this means is that where provision of HIV-related services is concerned government cannot hide behind availability of resources or lack thereof when called upon to fulfill its obligations.

5. Using the Current Human Rights Framework to Ensure Access to Better Health Related Services

Government policies and guidelines, international best practice and the constitutional jurisprudence that has been developed on the right to health are indicative of

---

70 As above, para 44.  
71 Note 69 above, para 28.  
72 Minister of Health & Others v Treatment Action Campaign & Others 2002 (5) SA 721 (CC); 2002 (10) BCLR 1033 (CC) (the TAC case). This is an appeal by the Minister of Health against a judgment granted in favour of the TAC by the High Court. In the High Court case the TAC challenge was brought on behalf of HIV-positive pregnant mothers who could not access treatment for mother-to-child transmission of HIV in the public sector. The case was brought when the government refused to roll out the provision of the programme to all the provinces. The TAC based its challenge on the fact that the government has an obligation in terms of section 27 of the Constitution to provide the drugs to all HIV-positive pregnant women in South Africa. Available at http://www.conCourt.gov.za/files/tac/tac.pdf (accessed 30 October 2004).  
73 Note 26 above, sec 27.
the responsibilities that society at large has towards people affected by HIV/AIDS. So far, all the groundwork has been done. The Constitutional Court has made its position clear on stigma and discrimination against PLHAs\textsuperscript{74} and also on the provision of health care services\textsuperscript{75} by vulnerable members of the community. What is outstanding is acceleration of a co-ordinated implementation of programmes that are related to the ideals that the human rights framework promises. This part looks at how the developed frameworks can be used to advance the right of individuals living with HIV/AIDS in rural communities, especially using the human rights approach.

5.1 Access to health-related information

Indeed the health care workers involved in the research blamed the cause of some of the problems experienced by the community on poverty, unemployment, prostitution and lack of information (coupled with ignorance).\textsuperscript{76} This lack of information has been associated with the inability of people to make informed choices bout their lives. Health care workers’ lack of information is responsible for people engaging in risky sexual behaviour, thereby making themselves vulnerable to HIV infection.\textsuperscript{77}

The research has also made it clear that rural communities are lacking in information on how to treat individuals affected by HIV/AIDS. Strategies aimed at addressing the needs of those affected in these areas have to focus on empowering those directly affected. Although there is general consensus that over the years people have been provided with information on HIV/AIDS, that is not the case for everyone involved. Although rural communities have heard about HIV/AIDS or are themselves infected or affected, they do not have an idea on how they could help themselves. Most people have heard about human rights and the Constitution but are clueless on how to use the Constitution to enforce their rights and thereby improve their lives.

PLHAs should be informed about their constitutional right to information that is necessary to make informed decisions about their health. The right to health as recognised in the Constitution\textsuperscript{78} cannot be exercised in a vacuum. It should be supported by attempts to ensure that people are provided with the necessary information that will make the right to make informed decisions a reality. The arguments about the right to information can be supported by the provisions of the ICESCR, which emphasizes that in the provision of health, states have an obligation to ensure “the creation of conditions that would assure to all medical services and medical attention in event of sickness”.\textsuperscript{79} For example, PLHAs have a right to insist on information regarding HIV testing, nutrition and supplements for those infected and most importantly, information about how to prevent infecting others and getting re-infected possibly with a different strain of the virus. This information might also be of assistance in enlightening them on how to deal with stigma and discrimination so that they do access services.

5.2 Access to health-related services

Inequalities in the distribution of services have made rural communities more impoverished than their urban counterparts. Service delivery in urban settings is of a better quality to that provided in rural settings. The inequality in the provision of services is contrary to the requirements in the Constitution that oblige the state to provide equal and universal access to everyone.\textsuperscript{80} That is also contrary to the sentiments expressed by the Constitutional Court in the TAC case,\textsuperscript{81} in which the Court made it clear that HIV/AIDS is an emergency and

\textsuperscript{74} Note 68 above.
\textsuperscript{75} Note 71 above.
\textsuperscript{76} See transcripts of interviews, especially focus groups 6 and 7.
\textsuperscript{77} Ibid.
\textsuperscript{78} Note 56 above.
\textsuperscript{79} Note 46 above.
\textsuperscript{80} See the discussion on government’s response to health care needs above.
\textsuperscript{81} Note 71 above.
provision of services for HIV/AIDS cannot be subjected to the test of progressively realisation of rights. Discrimination in the provision of health care services should not be tolerated.

5.3 Eradication of poverty

Because poverty hinders access to a number of services it is one of the factors that have to be explored when considering mechanisms to deal with the scourge of the epidemic. Most people are vulnerable to HIV infection because of their socio-economic conditions. Women are more on the receiving end of the burden caused by HIV/AIDS. They are more vulnerable to infection because of the inequalities in society (social and economic) and a general lack of access to resources. According to the UNAIDS report, because women are disproportionately affected by AIDS they are often driven to poverty as they have to divert their energies to more productive tasks, such as taking time off from work or school to take care of their sick relatives. Improving the lives of poor communities is therefore necessary to ensure that people do not put themselves at risk of infection.

6. Recommendations

The Tsvelopele Report outlines important recommendations that could be useful in addressing the problems faced by the Hammanskraal community. The recommendations in this chapter are an extension of those in the Report. The only difference is that emphasis is placed on what needs to be done to ensure access to quality health care services by people in rural communities.

First, it is clear that rural communities do not have access to information about their constitutionally protected rights. It is difficult for people to seek help when their rights have been violated if they are ignorant about the existence of those rights and how to enforce them. Institutions, such as the Human Rights Commission, that are mandated to promote and protect people’s human rights have a responsibility to ensure that people are educated about their rights and they should have access to institutions that would be in a position to assist them with enforcing their constitutionally protected rights.

Second, people affected by HIV/AIDS should be provided with medical literacy skills. It is critical that when people are infected they should know about the medical choices they can make to ensure that they live longer and healthier lives. Although medicines are now available to reduce the replication of the virus and the transmission of HIV/AIDS from mother to child, very few people seem to be aware of them. They are also unaware that in the absence of ARVs, a change in lifestyle (that is, better nutrition, exercise and taking nutritional supplements) could ensure that they live longer, healthier and more productive lives. Ignorance often leads to people thinking that HIV infection is a life sentence for which there is no cure available. That is and should not be the case.

Third, there should be a re-evaluation of the training needs of health care workers, home-based care providers and family members who look after their sick relatives. Health care workers have to be trained about the realities of HIV infection and the rights of patients with HIV/AIDS. In turn, that information should trickle down to everyone caring for PLHAs (such as family members and home-based care providers). The research has highlighted the fact that most of the health care workers have not been trained on management of HIV/AIDS. As suggested by the SAHRC Report, there needs to be an integrated management of HIV/AIDS at district and primary health care level.

83 Note 9 above, 19.
84 Note 18 above, 76. This suggestion is based on the fact that for poor communities access is possible only through these centres, that is, District and PHC centres.
7. Conclusion

An enabling environment has been created to ensure that human rights thrive. It is also true that a human rights culture does exist in most parts of the world, because there is universal recognition and acceptance of the body of human rights contained in international covenants and national Constitutions. This is equally if not more true in respect of South Africa. However, the persistent problem, especially among rural communities, is the lack of knowledge and most times mechanisms to exercise those internationally recognised rights.

The findings of the Tswelopele Project are not surprising. HIV-related stigma and discrimination are still the order of the day, especially in resource-poor settings where HIV infectivity rates are at their peak. The no-change scenario for HIV/AIDS stigma and discrimination can somehow be attributed to the fact that endeavours to deal with the epidemic have not been localised. Local communities that should be the intended beneficiaries are unfortunately the forgotten ones. International and national strategies that are intended to mitigate the impact of the disease do not trickle down to local communities. This is the result of bad management of the disease.

As demonstrated above, the state has made significant efforts to mitigate the impact of HIV/AIDS. However, the state has failed to ensure that these endeavours reach those mostly affected – rural communities. Efforts to empower members of these communities with information about not only their constitutionally protected rights but also about health care services available to them should be re-evaluated. It is obvious that health care services are not reaching the intended beneficiaries, and that stigma occasioned by HIV and AIDS is one of the reasons for this state of affairs.


Campbell, C “Selling sex in the time of AIDS: The psychosocial context of condom use on a South African mine” (2000) 50(4) Social Science & Medicine 479


Link, B and Phelan, JC “Conceptualizing stigma” (2001) 27(1) Annual Review of Sociology 363


Motsemme, N “What does it really mean to tell free and democratic stories?” (2004) Rhodes Journalism Review 3

Neethling, J; Potgieter, JME and Visser, PJ (1996) Neethling’s law of personality Durban: Butterworths


Richter, M “Nature and extent of discrimination against PLWAs in South Africa: interviews and a study of AIDS...


Tallis, J “AIDS is a crisis for women” (1998) 39 *Agenda* 7


Toole, MJ “Refuge for the selected few” (2001) 357(9266) *The Lancet* 1425


Zuberi, F (2004) *If you (be)come HIV positive, you will lose your human rights* Pretoria: Centre for the Study of AIDS

The AIDS and Human Rights Research Unit is based at the University of Pretoria and is a collaboration between the Centre for the Study of AIDS and the Centre for Human Rights. The Unit aims to undertake research on issues arising from the intersection of HIV and AIDS, on the one hand, and human rights, on the other.

*Righting stigma: Exploring a rights-based approach to addressing stigma* contains the report of a study about stigma in the Hammanskraal and Temba communities in Tshwane, Gauteng. *Righting stigma* further includes five essays, exploring in more depth the implications for human rights of the study results and interviews. The areas covered are gender and sexuality; disclosure and the right to confidentiality; HIV testing; social grants; and health care services.