HIV/AIDS, the disability grant and ARV adherence

This report presents selected findings from a project conducted in collaboration between Fafo and University of Cape Town, AIDS and Society Research Unit. Through triangulated qualitative and quantitative research methods, we studied whether people living with HIV faced trade-offs between treatment adherence and grant termination. Many people living with HIV in South Africa received disability grants prior to the antiretroviral roll-out in 2004. When antiretrovirals improve their health, they stand to lose the grant. We explore three main issues; whether people living with HIV faced trade-offs between treatment adherence and grant termination, the role of the medical doctors, as well as some gender aspects for people living with HIV in South Africa.

We find that while the antiretroviral roll-out is important, it is crucial to provide additional material resources, in order to make ‘positive living’ a reality. It is also important to understand that HIV-testing and disclosure have different implications for men and women. It requires tailored interventions to challenge stigma and encourage both men and women to test.
HIV/AIDS, the disability grant and ARV adherence
Summary report
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Preface

The AIDS and Society Research Unit (ASRU) at the University of Cape Town and the Oslo-based independent research institute Fafo developed a joint research proposal that was granted funding from the Norwegian Research Council for three years. The project was named ‘Poverty reduction strategies from a public health perspective; social grants, HIV/AIDS and the roll-out of HAART in South Africa’.

The project was initiated in 2007 and is now in its final stage of reporting and dissemination.

This report aims mainly at two groups: (1) the participants in the study – whether they are participants in the survey, in the in-depth interviews or in the focus group discussions – and (2) potential users of our data, be they national or local authorities, NGOs, CBOs or development agencies involved with issues concerning HIV/AIDS to whom our findings are relevant. We would like to thank the Research Council of Norway for funding this project. We would also like to thank all the participants for sharing their life-stories and experiences with us.

Oslo/Cape Town, August 2010
Marina Manuela de Paoli, Arne Backer Grønningsæter and Elizabeth Mills
Background

HIV in the world and in South Africa

According to UNAIDS, 33.4 million people are living with HIV. Of these, 22.4 million live in sub-Saharan Africa. The estimated 5.7 million South Africans living with HIV in 2008 make this the largest HIV epidemic in the world (UNAIDS, 2009). In 2008, over 250,000 people died of AIDS; the introduction of antiretroviral (ARVs) into the public health system has, however, resulted in a decline in AIDS morbidity, and in 2010, South Africa has the largest antiretroviral roll-out in the world. Given the scale of the epidemic in South Africa, this roll-out is lagging behind the targets for reaching 80 per cent of all those in need of treatment by 2011 (SANAC, 2007).

The HIV epidemic in South Africa highlights a history of structural inequality. In our research, we focused on the intersection of three areas of inequality: class, race and gender. In particular, we explored access to resources, such as disability grants, in the context of high levels of unemployment, and the gender dynamics of HIV prevention and treatment for men and women.

HIV prevalence is highest among South Africa’s majority black African population, which also has the highest rate of unemployment and the lowest per capita income of all the racial groups (Seekings and Nattrass, 2005). At the end of 2008, the official unemployment rate among the black population was 25.9 per cent, with unemployment in the townships even higher (Statistics South Africa, 2009). Despite high unemployment, South Africa’s welfare system is based on the premise of full employment, with no support system for the unemployed1.

HIV has a gendered face: women aged 19–25 are almost four times more likely to be HIV positive than men of this age group (HSRC, 2009) and almost one in three women aged 25–29 is HIV positive, compared to one in four men between the ages of 20 and 34 (ibid.). The stark contrast in HIV incidence between women and men indicates that, in South Africa, the burden of HIV affects women disproportionately more than men.

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1 An overview of South Africa’s grant system can be found at the following website: http://www.sassa.gov.za/content.asp?id=1000000511
Background
The disability grant

South Africa has one of the world’s largest non-contributory social-security systems (Gray, 2006). In 2007, altogether, there were 11.2 million people receiving social grants. Of these, 1.2 million received disability grants (Statistics South Africa, 2007). The disability grant amounts to 1,010 South African rand (ZAR) per month. The social grants provide financial assistance to people who are deemed ‘disabled’ and therefore unable to seek or sustain employment. Disability grants are awarded either on a ‘temporary’ basis (payments are provided for up to one year, whereupon the individual has to reapply for further support) or on a ‘permanent’ basis (usually requiring renewal every five years). The 2004 Social Assistance Act clarified the rules for awarding disability grants in general, but made no mention of HIV/AIDS.

People who are sick with AIDS or ill with HIV-related opportunistic infections may be unable to look for and to take up employment opportunities, in which case they qualify for disability grants. The purpose of the disability grant for HIV-infected persons is to provide support to individuals until they are healthy enough to re-enter the labour force and support themselves. According to Simchowitz (Simchowitz, 2004), different provinces in South Africa use different means of assessing disability, with some relying on evaluation by medical officers or district surgeons and others relying on an ‘assessment panel’. The Western Cape, the province in which we conducted our research, opted not to introduce assessment panels but to use medical officers to assess disability. A general rule that applies in most hospitals and clinics throughout the country is that an individual with a CD4 count of ≤ 200, which is roughly associated with clinical Stage 4 AIDS, meets the clinical criteria for receiving a disability grant. Prior to the roll-out of ARVs in 2004, many people living with HIV (PLWHs) received disability grants when they became sick from AIDS and unable to work. With access to ARVs, and therefore renewed health, many PLWHs stand to lose the grants as a result of their improved health. This is particularly problematic in South Africa with its high levels of unemployment and poverty (HSRC, 2009; Seekings and Nattrass, 2005).

1 USD = 7.4 ZAR

3 New national treatment guidelines were introduced in South Africa in April 2010, but for the purpose of this report and our analysis, we will work with the treatment guidelines that were applied during our research period.
Research methods and ethics

A triangulation of methods was applied: (1) in-depth semi-structured interviews with twenty-nine PLWHs; (2) in-depth semi-structured interviews with eight medical doctors working in the public sector throughout the Cape Peninsula; (3) three focus group discussions (FGDs) with programme managers, stakeholders and community workers; (4) a panel survey (KSPS) of 216 PLWHs receiving ARVs, and (5) a control panel survey (KPS) of 517 people of unknown HIV status.

The KSPS and KPS are a series of longitudinal panel surveys conducted in a peri-urban settlement in Cape Town since 2004. The 2007 KSPS and KPS are the third survey wave in this longitudinal study. In the 2007 survey questionnaires, the researchers included additional questions to obtain information on the potential trade-offs between health, economy and welfare.

Empirical research was conducted in 2007 and 2008 in a number of urban and peri-urban areas, including Khayelitsha, Nyanga, New Crossroads, Somerset West and Hout Bay. The purpose of the qualitative study was to collect a wide range of information with regard to challenges faced by PLWHs, to community-driven responses to these challenges, and to overarching recommendations by key stakeholders. For this reason, a number of key stakeholders were identified for participation in the qualitative research, including medical doctors, HIV counsellors, members of NGOs, community workers and PLWHs.

The main sources for this report are the qualitative in-depth interviews and FGDs, with supplementary information from the survey data. We have also referred to findings presented in previous articles and papers where the data from this project have been analysed and discussed.

The study was approved by the Ethical Board of the Centre of Social Science Research. The City of Cape Town gave the researchers permission to conduct research in principal health care centres and with health care professionals working in the public health sector. Informed consent was secured from each participant, and all names and identifying characteristics have been removed in order to ensure confidentiality. Social research on people living with HIV/AIDS (PLWHs) entails some special challenges as this is a stigmatised and vulnerable group. As researchers we were careful to avoid inadvertent disclosure of HIV status (as not all participants had disclosed their status). We sought to establish trust with the participants, ensured that their participation was voluntary, and that the interviews took place in locations that the participants had chosen, in order to safeguard confidentiality.
Access to social security

The roll-out of ARVs in 2004 changed the basic challenges for HIV-positive individuals in South Africa. Prior to 2004, many PLWHs accessed disability grants when they became sick with AIDS-related opportunistic infections. Once on ARVs, many lost the grants as a result of their improved health. Some participants, however, did not lose the grants, and some of them did not seem to understand why they still received the grants.

The loss of a grant has a substantial impact on socio-economic status and health. As the number of people losing their disability grants annually is likely to rise to about half a million by 2010, it is important to assess the consequences of grant loss and the measures taken to prevent or mitigate this shock. This potential trade-off could have serious social implications and may contribute to the development of resistance to ARVs.

The cohort of the quantitative part of the study is made up of PLWHs who initially accessed the disability grant, and they were among the first in South Africa to move on to ARVs. Consequently, this cohort experienced improved health, which jeopardised the extension of their disability grants.

Given that some of the PLWHs could no longer access disability grants, the finances of their entire households as well as their extended families were adversely affected. Loss of the disability grant also had social implications. The disability grant gave PLWH positive standing in their families. When the disability grant was terminated, the motivations for disclosure to the family were undermined.

Owing to the low income of many of the participating families, the PLWHs were regarded both as a source of access to income and as people in need of care. Many of the participants described both experiencing stigma and receiving care from their family members.

Engagement with state-run social services was highly complicated and fraught with difficulties. The main reason for PLWHs' having contact with the social services was to access the social grants. There seems to be a difficult relationship between the PLWHs and those handling the grant application.
**Ramifications of the disability grant for PLWHs**

**Unemployment and grants**

“I am fine. I can work. The government must produce more tablets... The people [PLWHs] must get stronger. The government must accept us [PLWHs]. We are HIV infected – everybody must accept us! We are not dead already! No, we are not dead! They must accept us, they must give us jobs, and they must treat us like anyone else [a person that is not HIV infected]. They must not think that an HIV-infected person is going to die tomorrow. They are not giving us [PLWHs] opportunities to be somebody! [...] So the government must not wait for somebody to die. The government must not wait until a person’s CD4 count is less than 200, because that person cannot do anything! You understand? They [the government] must look after and support us [PLWHs] [...] I can get sick two, three times a week, but I do not want to be sick. I do want to get a job!”

(HIV+ man aged 44)

<table>
<thead>
<tr>
<th>KSPS/KPS</th>
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<tbody>
<tr>
<td>50% of the participants in the KSPS were unemployed</td>
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<tr>
<td>46% of the control group in the KPS were unemployed</td>
</tr>
<tr>
<td>78% of households in the KSPS were receiving social grants as a part of their income</td>
</tr>
<tr>
<td>41% of the participants in the KSPS received disability grants</td>
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<tr>
<td>6% of the control group in the KPS received disability grants</td>
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</tbody>
</table>

Employment was desired by the HIV-positive participants, but it was a reality for very few. They struggled to maintain good health without employment, sometimes to the extent that hunger affected their adherence to ARV. It was important to adjust the conditions of employment to accommodate the health care needs of PLWHs.

Unemployment was a major theme among PLWHs who had recovered from AIDS (through ARV medication). Some participants lamented the fact that they were healthy and able-bodied but the employment sector was saturated, particularly for those seeking unskilled work.

Most of the participants said that unemployment and poverty were their main problems. Their HIV status was an additional barrier to getting into the labour market. As long as they were outside the labour market, they perceived managing their HIV status in a positive way to be difficult. The disability grant was therefore viewed as a temporary way out of this vicious cycle.
Ramifications of the disability grant for PLWHs

Use of disability grants

“The problem is that we have overcrowded families with huge numbers of children who are depending on one person who is ‘granting’. Our [my wife’s and my] parents are both ‘granting’, and it is the same situation. My mother is retired, but it is not easy for her to support [me] because there are other people she lives with [who depend on her grant].”

(HIV+ man aged 35)

KSPS

■ 98% of the HIV+ participants who received disability grants used the grants to cover general household expenses

The grant was used to contribute towards general household expenses. It was often the main source of income and sometimes the only one both for HIV-positive individuals and for members of their households.

General household expenses dominate the use of the grant money. For most participants, the disability grant not only covers their individual and household expenses, but also those of their extended families. This need for and use of the disability grant was one of the factors putting pressure on PLWHs who were ‘granting’.

Funeral expenses were the only other kind of major expenditure that was mentioned by the participants in both the survey and the in-depth interviews. The funeral traditions in South Africa represent an economic burden for many households, and AIDS seems to have added a new dimension to this burden.
Disability grant termination and ARV adherence

Loss of grants leading to stress

“You become sick once you lose your grant, because you become depressed. After that your CD4 count drops, because you don’t know what you’re going to eat. People become sick all the time because you need to take your medication. But, if you don’t have food, it’s difficult, and you cannot go back to your family. No one will help you. If you are unemployed, you will experience problems because you have to buy food and clothing and pay for funerals with that grant.”

(HIV+ woman aged 28)

KSPS

- 42% of the participants had experienced losing their disability grants
- 90% of those for whom the disability grant had been terminated reported that this had had a substantial impact on the household finances

When the ARV treatment leads to a higher CD4 count for the HIV-positive individual, the grant period usually ends. Termination of the disability grant can mean that the household no longer has a source of income. The recurrent loss of income when disability grants were not renewed had a substantial impact both on the individuals living with HIVs and on their households.

Loss of the disability grant as a result of improved health had a significant impact on physical and emotional health, and led to high levels of stress. Losing the grant has direct implications for PLWHs, as a healthy diet may no longer be accessible. This in turn undermines adherence to ARVs. This was confirmed in the interviews with the doctors who were responsible for recommending disability grants.
Disability grant termination and ARV adherence

Adherence to ARVs

“Oh no, I take my drugs every day, because I do care about my treatment and all that since I started to take my treatment [...]. It’s about my life!”

(HIV+ man aged 44)

“I just tell them [the doctors], sometimes, when I am hungry, I don’t take my ARV treatment, I just leave the tablets lying there [...] and then I’ll see [whether I have any food to eat] the following day.”

(HIV+ woman aged 30)

“My patients don’t take the tablets every day. They play with their health. The cleaners here at the clinic find lots of tablets dumped daily, in the yard, toilet. It is almost every day that one of my patients will tell me that they saw someone in the bathroom who dropped a handful of tablets in the toilet. Sometimes, I hear them when they discuss outside about manipulating the number of tablets. They calculate how many tablets they should be left with and they educate one another outside. They discuss among themselves that if you take your tablets every day, you will get better and your CD4 count will go up and that’s when the grant will stop. So they play with their health.”

(Male doctor)

KSPS

- 3% (n = 6) of the PLWHs stated that they had stopped taking ARVs
- 10% of the participants agreed that ‘it is a common strategy for HIV-infected people to stop taking ARVs in order to get sick and get the disability grant back’

Discontinuing the use of ARVs in order to maintain and in some cases to re-qualify for the disability grant was not a common strategy. The ARV adherence rate remained consistently high for HIV-positive participants in the panel surveys and according to those interviewed in the qualitative study.

There were, however, constant rumours that some people had stopped taking their ARVs in order to qualify for the grant and alleviate their financial problems.
When they were asked whether they would stop taking ARVs in order to get sick and therefore qualify for the disability grant again, none of the participants said that they would engage in this kind of practice. Thus, adherence to drugs was important, and a typical comment on this issue was made by one male participant who said: ‘It’s about my life.’

The interviews, however, suggested a number of subtle ways in which PLWHs may ‘tip the scale’ to lower their CD4 counts without stopping ARV use completely. Examples were increased alcohol consumption just prior to attending the clinic for a regular CD4 count check-up, and skipping some days of treatment.

It was difficult to take the drugs on an empty stomach. Unemployment, therefore, has practical consequences for the participants’ experience of poverty and their ability to maintain good nutrition alongside their ARV regimens.
Incentive to trade off health for income

This page refers to an article published by our colleagues in *AIDS and Behaviour* (Venkataramani et al. 2009).

*Descriptive statistics for health and income by year and by employment status for those who lost disability grants between 2004 and 2006*

<table>
<thead>
<tr>
<th>Sample</th>
<th>2004/2005</th>
<th></th>
<th>2006</th>
<th></th>
<th>2007</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Employed</td>
<td>Unemployed</td>
<td>Employed</td>
<td>Unemployed</td>
<td>Employed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Sample size</td>
<td>22</td>
<td>43</td>
<td>28</td>
<td>37</td>
<td>33</td>
<td>22</td>
</tr>
<tr>
<td>Average individual income ($ US/month)</td>
<td>331</td>
<td>126</td>
<td>194***</td>
<td>9***</td>
<td>198***</td>
<td>28***</td>
</tr>
<tr>
<td>Average household income ($ US/month)</td>
<td>429</td>
<td>265</td>
<td>367</td>
<td>173**</td>
<td>307**</td>
<td>194*</td>
</tr>
<tr>
<td>Self-reported health (1–5 scale, 5–excellent)</td>
<td>4.22</td>
<td>3.74</td>
<td>3.89</td>
<td>3.45</td>
<td>4.30</td>
<td>3.88</td>
</tr>
<tr>
<td>Self-reported side effects (number experienced)</td>
<td>3.74</td>
<td>2.37</td>
<td>1.57</td>
<td>3.76**</td>
<td>1.37</td>
<td>1.68</td>
</tr>
</tbody>
</table>

Significant values are for T-tests comparing outcomes from 2006 and 2007 to those from 2004/2005 wave within employment status groups

*** P < 0.01, ** P < 0.05, * P < 0.10

Given high rates of unemployment, the loss of a grant has a substantial impact on socio-economic status and health. Disability grant termination was associated with lower individual and household incomes, especially for those who, after grant loss, could not find employment. Households without disability grants also had fewer dependants – probably either the consequence of income loss or a mechanism to cope with it. Despite these findings, however, there is no association between grant loss and self-reported health status or side effects from ARVs. The results of various empirical tests did not support anecdotal evidence that individuals declined or modified treatment to continue receiving disability grants, despite potentially large decreases in individual and household income. This cohort of ARV recipients did not appear willing to sacrifice health for continued access to the disability grant.

The disability grant system did not work as it was intended. Individuals who a priori should have been ineligible for the disability grants continued to receive them, suggesting that oversight of grant administration may be ineffective or that medical officers may sympathise with the plight of their patients and help them ‘play’ the system. It also suggests that the means test is far from foolproof, given that some people on disability grants were also working.
Doctors’ role and their relationship with PLWHs

Criteria for grants

“The most difficult thing about being a doctor is that you have to write disability grants. It is like you are God. You just have to look at the person’s face and decide about whether they qualify or not.”

(Female doctor)

“It depends on the heart of the doctor sometimes ... [talking about extension of the original disability grant time period]. If the doctor has got your sympathy then he can do that.”

(HIV+ woman aged 28)

Doctors are principally responsible for recommending whether or not PLWHs are eligible for grants, and for stipulating the duration of each grant award. This highlights the pivotal role of doctors in shaping the physical and financial well-being of PLWHs.

Many doctors stated that there were no clear national guidelines concerning eligibility for the grant. In one sense, this gave them some flexibility in evaluating grant eligibility, but it also increased the pressure on them. Some doctors acknowledged that, in addition to health criteria such as CD4 counts, they also used social criteria when deciding who qualified for disability grants. Doctors reported feeling uncomfortable and pressured to recommend disability grants for PLWHs. At the same time, PLWHs’ expectations surrounding the disability grant were referred to as the most important challenge facing the doctors’ daily work.

The participants echoed this sense that the doctors were like God, dictating the quality of their life. They felt uncomfortable with the extent to which doctors shaped their lives. The participants in the qualitative study reported feeling helpless when confronted with the doctors’ inherent power to make decisions that affected their financial and physical well-being. The absence of clear guidelines for recommending the disability grants reinforced the participants’ perception that doctors made ad hoc decisions that were inconsistent, and dependent on subjective factors: ‘it depends on the heart of the doctor’, as one participant stated.
Doctors’ role and their relationship with PLWHs

Doctors under pressure

“Nationally there are no clear guidelines. It varies from province to province, and even in this province it varies from doctor to doctor. Some doctors are hesitant to write a disability grant while others give just about anyone a disability grant. Some doctors still prescribe permanent disability grants – duration five years – while other doctors never do it. Locally, there has been some sort of agreement – if your CD4 count is less than 200 then you qualify for a grant. However, some doctors will give it to you for six months and other doctors will give you a twelve-months grant.”

(Female doctor)

“I always enquire about their employment. If they are employed, and their general health condition is good, I do not offer disability grant. In cases where there is no income through employment, I offer disability grant. I have offered disability grant to all those who start ARVs regardless of their CD4 count. I have even prescribed ARVs for patients whose CD4 count is above 200. I base my assessment for initiation of ARVs on the general health condition of the patient, tuberculosis relapse and patients’ readiness. I just about always ask for a twelve-months grant period. I do not know about any cut-off points in earnings for meeting the disability grant eligibility.”

(Female doctor)

“Sometimes when they bring their kids and you can see that they are hungry. But then again, the guidelines state that you cannot give this person a disability grant. You know what is going on at home and that there are no social workers to take care of the person. You know that you can help, but then at the same time you do not want to be seen as the fraudulent doctor. I guard against that because one day when you give that disability grant and SASSA—which decided to do an audit—then you may be seen as fraudulent. But honestly speaking, I have been fraudulent, two or even three times, not a lot. I mean I am very careful. They think I have empathy and understanding, because where they come from is probably where I come from.”

(Female doctor)

“The grant is coming and going.”

(HIV+ man aged 44)

*South African Social Security Agency*
The doctors’ assessments emerge as the most important grounds for terminating the grant. Before the era of universal access to ARVs, permanent disability grants were provided to PLWHs who were in the final stage of AIDS. The doctors varied greatly in the criteria they used to assess eligibility and whether they prescribed ‘temporary’ or ‘permanent’ grants. In the quotations above below, the doctors describe the ways in which doctors reach decisions about disability grant eligibility.

The rationale for prescribing grants differed between doctors, which reinforced the participants’ belief that the decisions regarding disability grant eligibility and duration were ad hoc and inconsistent. For example, some employed patients with high CD4 counts were still receiving disability grants, while some unemployed patients with low CD4 counts were unable to receive the grant.

Some of the doctors believed that some of their patients used HIV as a way to get grants. These doctors believed that unemployment was the problem and that the measures should be focused on unemployment instead of disability. On the other hand, they were aware that the disability grant gave new opportunities to PLWHs in an everyday situation where it was hard to manage the financial demands that households were facing. This also puts doctors under pressure to balance the biomedical criteria for grant eligibility against other criteria such as the individual's circumstances, unemployment and poverty.

The participants in the in-depth interviews were unclear about the ways the doctors decided on grant eligibility and the ways that social services managed the grants. This reinforced their sense that doctors and social-welfare professionals were inconsistent in managing disability grant applications.

Some PLWHs clearly indicated that the application procedure was difficult and suggested that it would be useful to have professional people assisting them in the process.

In most cases, grant recipients did not know how long they were eligible for the grant, and a few of the participants who had regained health were unsure why they continued to receive the grant.
Gender and HIV
HIV prevention and ideas of masculinity

“[A] thing which is a barrier: it is a tradition that men believe that they would not have sex with plastic [condoms] – it is a taboo. Tradition becomes a barrier. Men want flesh to flesh; they believe that what makes a man is flesh to flesh.”

(Participant, men’s FGD)

“They [men] are saying that chances of getting AIDS [as a] man is very little because we are not like woman.”

(Participant, men’s FGD)

“I can’t trust a man and go to bed with a man who’s saying that we’re going to use a condom. It’s a lie! There are few men who know how to use condom because men never experience it in the first place. Now the condom is new to them, very new to them. So I can’t say now I can go with a guy because he will say we going to use condom. It’s a lie.”

(Participant, NGO FGD)

“Men won’t go for VCT [voluntary counselling and testing]. They want to make their partners pregnant. Then if the partner comes back from the clinic and says that ‘I’m negative’, he will be happy because he thinks he is negative. But if the partner says ‘I’m HIV positive’, that will create domestic violence. He will say, ‘You are the one who came with this thing. You were sleeping around.’”

(Men’s FGD)

“You would find that men, when it comes to VCT, they don’t want to come [forward, i.e. disclose their positive HIV-status]... You know, most of our men [in our support group] are still ignorant... They even tell us that, ‘We don’t know our status because we are scared of going there [to the clinic].’ And what I found out is that men want to make their partners or girlfriends pregnant, so that they can find out their status. So they think they know their status, though they don’t know their status.”

(Men’s FGD, 2007)

According to the male participants in the qualitative study, the men perceived themselves and other men to be invulnerable to HIV infection; conversely, men attributed vulnerability to infection to women, and women were also accorded blame for transmission when men tested HIV positive. The HIV-positive men we interviewed linked this perception of invulnerability to men’s decisions not to use condoms, and attributed their HIV infection to this misconception of strength vis-à-vis women’s vulnerability.

Gendered dichotomies that align illness with weakness and being a woman, and invulnerability to illness with strength and being a man, may contribute to men’s being more reluctant than women to practise safe sex, test for HIV, and receive treatment. These dichotomies also rein-
force the victim/perpetrator model that implicitly places blame on men and fails to account for the range of ways in which men and women negotiate structural and social constraints as they navigate their physical, financial and emotional well-being.

Constructions of masculinity were also linked to reluctance on the part of men to access health resources, including voluntary counselling and testing services. Women were likely to find out their HIV statuses before their male partners, particularly as women entered the health system to receive antenatal care.

The assumption that women would test for HIV when receiving antenatal care also prompted another linked finding: proxy-testing. The men and women in the study said that men ‘proxy-tested’ for HIV by insisting on unsafe sex with their partners to make them pregnant and then waiting to hear of their test results following their antenatal check-ups. The men would base their conclusions about their own HIV status on the test results of their partners.
Gender and HIV
Disclosure has different consequences for men and women

“I was suffering, you know...... Because I didn’t have money for this child of mine. And the father of this child ran away when I told that I am HIV positive. I have never seen him again.”

(HIV+ woman, aged 25)

“Sometimes he comes to see the kids [He] stays in a car outside the gate and calls the children to him.... I just thought: ’Maybe it’s God’s way of separating us.’ ”

(HIV+ woman, aged 42)

The blame for contracting HIV is apportioned to the first one to disclose in a relationship. Testing entails a responsibility of keep. The fact that many pregnant women are invited to participate in PMTCT (prevention of mother-to-child-transmission of HIV) programmes when going for antenatal care means that many women learn of their own status before their sexual partners learn of theirs. The women are often discriminated for being the first in the household to disclose a positive HIV status. This deflects attention from the potential scenario that the men have, in fact, contracted HIV first and transmitted it to their partners.

Many women reported experiencing blame, abandonment and abuse upon disclosure of their HIV-positive status to their partners following their HIV tests. This places women in an untenable position where they are required to access health care for their children, to test for HIV, and bear the brunt of responsibility for ’bringing HIV into the home’ when they disclose their status to their partners. After a 15-year-long marriage, the 42 year old woman cited above was deserted by her husband when she disclosed that she had tested positive in the PMTCT clinic when pregnant with their third child.

We therefore recommend that HIV testing campaigns also develop targeted strategies to encourage men to test in order to reduce the burden of responsibility placed on women by their capacity to bear children.
How health care is gendered

“You would find that men, when it comes to VCT, they don't want to come forward... You know, most of our men [in the support group] are still ignorant... They even tell us that, 'We don't know our status because we are scared of going there [to the clinic].’ And what I found out is that men want to make their partners or girlfriends pregnant, so that they can find out their status. So they think they know their status, though they don't know their status.”

(Men’s FGD, 2007)

Biomedical health services that cater for women’s reproductive health may implicitly place the responsibility for knowing one’s HIV status on women.

Active participation in clinics may enhance women's physical health. It may also undermine their well-being by placing the responsibility of knowledge on them. The burden of proof for behavioural change through disclosure is placed on women. That makes women vulnerable to HIV-related stigma within sexual and social relationships.

Women's capacity to bear children, in sub-Saharan Africa, often assumes that women are primarily responsible for children's health. This can also create a form of gendered discrimination against women because men are absent from the process of ensuring child health. For example, many of the female participants reported that they were reluctant to collect infant formula from the clinics because by doing so they would unintentionally disclose their HIV status to other people attending the clinics. Further, women felt pressured to breastfeed their babies when in public, in addition to formula-feeding their babies, because they did not want to be identified as HIV positive by other people who assumed that a decision not to breastfeed was linked to HIV-positive status.

Men’s sense of invulnerability to HIV infection and their perception of clinics as ‘women’s spaces’ may reinforce men’s reluctance to test and thus their delayed access to ARVs; this in turn undermines men’s health.
Infant feeding and stigma

“You know last year when I was dealing with PMTCT... I discovered that most of the mothers never disclose to their boyfriends... It’s like there are many people staying together now but the problem is that it’s hard to disclose your status to your boyfriend because this boyfriend might think you is the one brought that disease into the house.”

(NGO FGD)

“Women have to go to the clinic to get that Pelagon. I think it’s a stigma for them [to get Pelagon]. Sometimes these women are not ready to disclose. In the part of the clinic where women sit with their babies, some [HIV-positive] women breastfeed because they not ready to disclose and then the children get infected.”

(HIV+ woman, aged 30)

<p>| How did you or your partner feed your last-born child for the first month? (KSPS) |
|-------------------------------------------------|-----------------|----------------|</p>
<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusive breastfeeding</td>
<td>58</td>
</tr>
<tr>
<td>Mixed feeding (infant feeding formula, cow's milk and breast milk)</td>
<td>19</td>
</tr>
<tr>
<td>Purchased infant feeding formula</td>
<td>31</td>
</tr>
<tr>
<td>Free clinic supply of infant feeding formula</td>
<td>79</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>190</td>
</tr>
</tbody>
</table>

The recommendations concerning infant feeding vary between the provinces of South Africa. In Western Cape, the official infant feeding policy in 2007 stated that women with HIV should be advised not to breastfeed. They were given infant feeding formula free of charge for a six-month period. This policy was not in line with the UN policy documents/guidelines from 2001 and 2006, which generally supported breastfeeding and suggested that it should be protected, promoted and supported.

We wanted to explore how the official infant feeding policy in the Western Cape in 2007 had been implemented. Most of our participants adhered to this recommendation and did not breastfeed. They all experienced difficulties at six months, when the free infant feeding formula ceased to be available. No one had received specific guidance on how to use infant feeding formula.
South Africa is home to 5.7 millions of the 22.4 millions people living with HIV in sub-Saharan Africa (UNAIDS, 2009). In order to address the myriad economic, social and political ramifications of HIV in South Africa, we need to adopt a multi-pronged approach to promoting prevention, treatment and care. Our research project explored a range of implications of HIV. The purpose of our research was, first, to establish a set of triangulated research findings, and second, to use our research to support interventions that address the socio-economic ramifications of HIV and AIDS in South Africa. In this final section, we move from presenting our research findings to considering some implications of our research for policy development and implementation.

**Breaking the vicious cycle of poverty and unemployment is critical for ensuring positive living with HIV/AIDS and ARV treatment.**

The AIDS treatment landscape has changed significantly in South Africa over the past decade. In 2010, South Africa has the largest antiretroviral programme in the world. The provision of treatment has ramifications, as described above, for securing and sustaining long-term health for HIV-positive people. The recovery of health through ARVs has also changed the terrain for providing disability grants to PLWHs; with ARVs, HIV is a chronic manageable illness, and does not signify imminent death or disability. As a result, many members of the study cohort moved off of their disability grants once on ARVs, as a result of their improved health.

As we move forward into the next decade, policy makers and implementers need to be cognisant of the high levels of poverty and unemployment that characterise the lives and households of many PLWHs in South Africa; ARVs alone will not suffice to sustain life.

Broad networks of support – social, medical and financial – need to be made accessible to PLWHs in order to support them in maintaining their health, and sustaining their lives.

It is also important to adjust the conditions of employment to accommodate the health care needs of PLWHs. This suggests that current definitions of ‘disability’ used in conjunction with assessing grant eligibility for PLWHs should be revised to recognise some of the longer-term implications of living with HIV and adhering to ARVs.

**Loss of a disability grant had significant implications for household income, and access to basic nutrition; this in turn affected the participants’ ability to adhere to their treatment.**

The disability grant was viewed as a temporary strategy for breaking the cycle of poverty and unemployment experienced by PLWHs and by members of their households. According to the quantitative data, 98 per cent of the participants used disability grants to cover household expenses.
In order to adhere to ARVs, and live healthy lives, PLWHs need access to nutritious food. The disability grant, in light of high levels of poverty and unemployment, enabled PLWHs to access food. Participants reported that the main reason for terminating ARV treatment was their inability to access food. Given the importance of nutrition for adherence, and the likelihood of losing a disability grant when on ARVs, we recommend further research into poverty mitigation strategies that extend beyond (and include) social security nets such as the basic-income grant. Alternatives to disability grants, such as the chronic-illness grant or basic-income grant, would enable PLWHs to make ‘positive living’ a reality. Furthermore, incentives to create more jobs are pivotal. Given that unemployment is a central problem for many people with HIV, an unemployment grant would also be an important improvement. Making finances more predictable for individuals and their households is also crucial for the treatment and support of PLWHs.

Our research established that it was not a common strategy to compromise one’s health in order to qualify for the disability grant. There were, however, suggestions that other PLWHs (i.e. not the participants but people they knew) ‘adjusted’ their treatment regimens in an attempt to bring down their CD4 counts without seriously jeopardising their health, in order to qualify for renewal of their grants. As stated above, one of the most important factors affecting adherence was nutrition; without food, the participants reported that they struggled to adhere optimally to their treatment.

**The absence of a coherent national grant-awarding framework allows for greater flexibility on the part of the doctors, but also increases pressure on doctors and offers scope for abuse.**

The absence of a coherent grant eligibility framework reinforces insecurity among PLWHs, and also opens the way for unequal access to social resources. On the other hand, the absence of clear guidance also enabled doctors to assess grant eligibility flexibly; this also increased the pressure placed on doctors. The relationship between doctors and PLWHs revolves around life – both in terms of accessing essential life-extending medicines, and in terms of accessing social grants that ensure basic nutrition, for example, in a context of desperate poverty and unemployment.

**Social, financial and psychological support networks are invaluable for PLWHs as they promote overall health and well-being among PLWHs.**

Promoting acceptance by disclosure of one’s HIV-positive status, to the point that one respondent said ‘They call me Mr HIV’, is a central component of an effective personal and community strategy for counteracting stigma, and of providing support to PLWHs. This strategy also requires significant state and community collaboration in which structural factors (such as unemployment and poverty) and psycho-social factors (such as gender inequality, depression and stigma) are challenged, thus creating an environment in which all people in South Africa affected by HIV are able to thrive.

In the townships, and particularly in Khayelitsha, where we conducted part of the research, there are many community-based support groups for PLWHs and, consequently, local activism is strong. These groups play an important role in both prevention and care, and are an important example of the need for a state–community partnership in the field of HIV and AIDS.
Masculinities that proscribe safe sex and valorise invulnerability need to be reconfigured in order to promote prevention.

It is fundamentally erroneous to construct HIV prevention and treatment interventions that focus on women as the solution and men as the problem. Beyond failing to address the relational nature of gender, these interventions cause further damage by reinforcing unconstructive dichotomies and alienating men from constructively engaging with women to ensure gender equality as a means of achieving well-being within the matrix of social, emotional, financial and physical well-being. The research pointed to the value of moving beyond static constructions of gender, and facilitated a reappraisal of the dynamics of HIV infection, prevention and treatment. In order to eliminate the high levels of HIV transmission among young people, and particularly among young women, policy makers and practitioners also need to engage with men.

Constructions of masculinity that valorise strength encouraged men to believe they were not vulnerable to infection, and therefore could safely practise unprotected sex. Our research engaged with constructions of masculinity linked to constructions of tradition; the men reported that ‘traditional values’ proscribed using ‘plastic’ (condoms) because it was not traditional. These findings have implications for women, particularly given that current prevention techniques are male-centred and rely on men to agree to using condoms. Microbicides are currently still under development and latest research findings indicate that the use of microbicides reduces transmission by 39 per cent (Sokal et al., 2010). Further, female condoms are even less accepted than male condoms and are difficult to use. The findings also have implications for men, given that the perpetuation of a belief in men's invulnerability (linked to constructions of strength) places men at risk of contracting HIV through unsafe sex.

In order to address the feminisation of the HIV epidemic, policy makers and practitioners need to disrupt reifying dichotomies that place women and men in respective categories of victim/perpetrator, passive/active, weak/strong, and deserving of sympathy/blame.

Testing and disclosure are gendered, have different implications for men and women, and require tailored interventions to challenge stigma and to encourage both men and women to test.

Many women resented the responsibility and blame linked to testing for HIV during antenatal care procedures in clinics. The women reported that disclosure precipitated blame, abandonment and violence from their male partners; the male participants confirmed this, suggesting that men ‘proxy-test’ by making their partners pregnant, hoping the partners will test for HIV. In the process of ‘proxy-testing’, men attempt to deduce their statuses from their partners’ test results, and, because women test first, they are frequently accorded responsibility for contracting the virus first, and ‘bringing it into the house’.

The blame and stigma linked to testing and disclosure therefore fall along gendered lines, and require further research. It is particularly important to develop strategies to encourage men to test, and to dispel the notion that it is possible to deduce one’s status from one’s partner’s status.
Constructions of masculinity discourage men from accessing health services, which undermines men’s health and increases the risk of HIV-related mortality for men as opposed to women.

We also recommend that interventions move beyond encouraging men to test, and that they also encourage men to access health care resources more generally. Women frequently access health resources through neonatal care practices whereas, according to the findings, constructions of masculinity discourage men from acknowledging vulnerability, including susceptibility to illness and the need to access medication.

*Formula-feeding practices can precipitate stigma, and therefore education campaigns need to be developed to dispel rumours and discourage mixed-feeding practices.*

Women also reported experiencing stigma linked to infant feeding practices; if women used infant formula rather than breastfeeding their children, they were branded ‘HIV positive.’ In order to avoid stigma linked to HIV, women reported using mixed infant feeding methods depending on the people around them. Mixed feeding undermines the integrity of infants’ digestive tracts, and increases their susceptibility to HIV infection; it is therefore necessary to develop strategies that address stigma surrounding formula-feeding practices.
Publications from the project

Articles


Grønningsæter, A.B., M.M. de Paoli (forthcoming), HIV/AIDS, stigma and mental health in a comparative perspective

Nattrass, N. (2009), Poverty, sex and HIV. AIDS and Behavior, P 833-840, Volume 13, Number 5, ISSN 1090-7165 (Print) 1573-3254 (Online)

Venkataramani, A.S., B. Maughan-Brown, N. Nattrass, J.P. Ruger (2009), Social grants, welfare and the incentive to trade-off health for income among individuals on HAART in South Africa. AIDS and Behaviour (Published online http://www.springerlink.com/content/302717ugq4375868/fulltext.pdf?page=1), ISSN 1090-7165 (Print) 1573-3254 (Online)

ASRU-CSSR Working papers


**Academic dissertations**


Coetzee, C. (forthcoming). *Having the HAART to live: The impact of HAART on labour market participation for patients in Khayelitsha who have been on treatment for more than three years*. PhD candidate in the Department of Economics, University of Cape Town

Kane, D. (2007). *Women’s Experiences of HIV, Unemployment, and Motherhood in Site B, Khayelitsha*. MPhil graduate in the Department of Sociology, University of Cape Town

Lane, H. (2007). *The impact of HAART on HIV Testing in South Africa*. MPhil graudate in the Department of Sociology; University of Cape Town

Maughan-Brown, B. (2009). *HIV/AIDS-related stigma in Cape Town, South Africa*. PhD graduate in the Department of Economics, University of Cape Town

Mkwanazi, N.B. (2009), (Quota programme student). *A Qualitative Assessment of the Experiences of HIV-infected Mothers and the Perspectives of Their Counsellors and Close Social Networks*. Master thesis, Institutt for allmenn- og samfunnsmedisin, Universitetet i Oslo (Supervisor: Marina Manuela de Paoli)
Presentations


Maughan-Brown, B. (2008), A panel analysis of HIV/AIDS-related stigma in Cape Town, South Africa. [THPE1046]. Oral presentation at the XVII International AIDS Conference in Mexico City, Mexico, August 3–8


Nattrass, N. (2008), Ranking government commitment to providing antiretroviral treatment using cross-country regression analysis [MOPE0900a]. Poster presentation at the XVII International AIDS Conference in Mexico City, Mexico, August 3–8

Internet publication

All the ASRU working papers has been published on the internet – see www.cssr.uct.ac.za/asru and also as indicated as direct links to the respective reports (above)

Fafo has established a theme-site where the HIV/AIDS research of Fafo is presented. This includes information about and some publications from this project. http://www.fafo.no/pro/SVP/hivaids.html


Seekings, J. & N. Nattrass (2005), Class, race and inequality in South Africa. Yale University Press


Sokal, D. et al. (2010), Safety of 1% tenofovir vaginal microbicide gel in South African women: results of the CAPRISA 004 trial [TUSS0503]. Oral presentation at the XVIII International AIDS Conference. Vienna, Austria, July 18–23


This report presents selected findings from a project conducted in collaboration between Fafo and University of Cape Town, AIDS and Society Research Unit. Through triangulated qualitative and quantitative research methods, we studied whether people living with HIV faced trade-offs between treatment adherence and grant termination. Many people living with HIV in South Africa received disability grants prior to the antiretroviral roll-out in 2004. When antiretrovirals improve their health, they stand to lose the grant. We explore three main issues; whether people living with HIV faced trade-offs between treatment adherence and grant termination, the role of the medical doctors, as well as some gender aspects for people living with HIV in South Africa.

We find that while the antiretroviral roll-out is important, it is crucial to provide additional material resources, in order to make ‘positive living’ a reality. It is also important to understand that HIV-testing and disclosure have different implications for men and women. It requires tailored interventions to challenge stigma and encourage both men and women to test.