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From Rhetoric to Reality: An Empirical Appraisal of South Africa's 2007-2011 HIV/AIDS National Strategic Plan

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Abstract

The unprecedented and collaborative development of the 2007 – 2011 HIV & AIDS and STI National Strategic Plan (NSP) reflects government and civil society's joint commitment to enhancing the lives of South Africans in the face of the country's HIV epidemic. This paper explores the practice of policy; areas of dissonance and convergence between health policy rhetoric and reality are analysed through the lens of a qualitative research study conducted in 2008 with 76 HIV-positive respondents in Khayelitsha, Cape Town. Through an analysis of health policy and corresponding research findings, this paper seeks to strengthen policy implementation and interventions for people affected by HIV in South Africa. The paper centres on the following three key priorities, as stipulated by the NSP: HIV prevention; treatment, care and support; human rights and access to justice. In line with the first priority, the research findings highlight the value of tailored prevention programs for sero-discordant couples to prevent horizontal transmission, and for HIV-positive couples to prevent HIV re-infection. The second priority, the provision of treatment, care and support, is negatively constrained by limited human and infrastructural capacity within the national health system. This finding points to the value of implementing task shifting in order to improve health care outcomes, particularly for rolling out antiretroviral programs in line with the NSP target to reach 80% of those in need of ARVs. The third priority underlines the importance of addressing HIV as a human rights issue; the findings indicate that the respondents continue to struggle with experiences of stigma within their community, but their experience of stigma within their families has significantly decreased. This paper proposes a set of recommendations based on the findings of this study in order to engage directly, and constructively, with the NSP's key policy priorities.

Introduction

The Global Human Development Report[1] indicates that the Human Development Index[2] (HDI) is improving for countries throughout the world, with two exceptions: post-soviet states and Sub-Saharan Africa (SSA). HDI declines in Sub-Saharan African countries are attributed, primarily, to the devastation exacted by the HIV pandemic and concomitant mortality. South Africa has the largest economy in SSA and, along with Botswana, is one of the wealthiest states in the region. This contrasts with more economically underdeveloped countries that have had far more successful national responses to the HIV pandemic. Uganda has a per capita public expenditure of $4, and has been touted up until recently as a role model for other countries dealing with HIV in SSA[3]. More recently, the UN has praised Zimbabwe, a country riddled with conflict and poverty, for signs of a declining national HIV prevalence (UNAIDS, 2008). Like Uganda, there is evidence of a decline in HIV prevalence among pregnant women in urban parts of Kenya (ibid). All of the above countries, particularly Zimbabwe and Uganda, have struggled under despotic regimes, debt and with far fewer resources to commit to public services, like education, sanitation and health care than South Africa. However, with an epidemic affecting 11% of its population (Shisana et al., 2009), South Africa remains one of the hardest hit countries in the region.

The 2007 – 2011 HIV & AIDS and STIs National Strategic Plan (NSP) is a comprehensive health policy to curb the impact of HIV in South Africa over five years from 2007 to 2011. The NSP was developed through extensive consultation across government departments and with civil society organisations and is a product of broad consensus across governmental and non-governmental sectors. As discussed below, the NSP outlines key priority areas, objectives and a set of targeted interventions to stem HIV incidence and provide treatment and support to those affected and infected by HIV. In line with the Millennium

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[1] http://hdr.undp.org/reports/global/ accessed May 2009.
[2] The HDI measures well-being using the three basic dimensions of human development, namely life expectancy (at birth), adult literacy (measured through the combined primary, secondary and tertiary gross enrolment ratio) and gross-domestic product (per capita at purchasing power parity in $US). http://new.hst.org.za/indic/indic.php/83, accessed 2009.
[3] Uganda's successful response to HIV has partly been attributed to the overt political commitment to reduce transmission and increase treatment (O'Manique, 2004). The role of political leaders in addressing HIV, however, has also been questioned by theorists who claim that political constituencies do not demand accountability from political leaders on issues like HIV and AIDS (de Waal, 2005).

Development Goal (MDG) to reduce and reverse the HIV epidemic, the NSP stipulates two main goals for the period 2007 – 2011. One, a 50% reduction in the number of new HIV infections by 2011. Two, the creation of an 'enabling environment' in which the impact of HIV and AIDS on individuals, families and society is reduced through expanding access to treatment, care and support to 80% of the HIV-positive population (NSP, 2007).

Policy implementation, however, presents a range of challenges to government and civil society. As a multi-sectoral policy, responsibility for implementation lies with a range of government departments and non-governmental organisations. Cabinet, the highest political authority in South Africa, has conferred responsibility for the NSP's implementation on to the Inter-Ministerial Committee on AIDS (IMC)[4] and the South African National AIDS Council (SANAC). SANAC's principle objectives include advising government on HIV/AIDS policy and strategy; the creation and support of partnerships to expand the national response to HIV and AIDS in South Africa; to implement sectoral interventions on HIV and AIDS; to oversee the monitoring and evaluation of the NSP (NSP, 2007).

Political leadership is intrinsically connected to policy development and implementation. The Chairperson of SANAC is the Deputy President of South Africa. In the course of the 2007 – 2011 NSP's life-span, SANAC has fallen under the leadership of three Deputy Presidents. SANAC's ability to implement policy was initially constrained by the poor scientific governance of HIV and AIDS under the former Minister of Health's leadership, Dr Manto Tshabala-Msimang. Following former President Mbeki's dismissal in 2008, a new Minister of Health was appointed, with positive consequences for SANAC's operational structures due to Minister Hogan's unequivocal evidence-based approach to the science of HIV and AIDS treatment. In May 2009, South Africa's health policy entered a new phase of leadership with the announcement of a new cabinet by the new president, Jacob Zuma. Aron Motsoaledi (a former provincial minister of education and a medical doctor) was appointed Health Minister and Barbara Hogan was given a new ministerial portfolio.

Although political leadership significantly informs the development and coordination of health policy, it is also important to contextualise policy implementation within a broader historical, social and political framework. In

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[4] The IMC incorporates the following government departments: Health; Social Development, Education, Agriculture and Land Affairs, Mining, Public Service and Administration.

1994 the democratic government inherited a health system that was committed to supporting the apartheid government and failed to provide adequate or equitable health care (Buch, 2000; De Beer, 1986; Wilson and Ramphele, 1989). In order to redress the fragmentation of the apartheid government's health care system, the government established a unitary health care system, with a single national department and nine provincial Health Departments (African National Congress, 1994; Buch, 2000). Within this unitary health system, there are four different levels of health services: National, Provincial, District and Community (African National Congress, 2001). The African National Congress argued that decentralization of health services in South Africa would generate a more effective distribution of health services, reaching the people who had been disadvantaged under Apartheid:

> "One of the aims of this [NHS] plan is to decentralize management of the delivery of services to provinces, districts and institutions in order to create efficiency, local innovation, empowerment and accountability." (African National Congress, 1994: 59).

Since 1994, the reformulation of the health care system had been constrained by the historically impoverished health care infrastructure the state inherited alongside the rapid escalation of the HIV epidemic and other diseases like tuberculosis. In 2009, the public health system continues to struggle to cater to the health needs of its clients. The human resource crisis (most recently evinced in public health doctors' striking for better working conditions in 2009), has significant ramifications on health care provision, and correspondingly, on health policy implementation in local and district level facilities.

Given the scale of the epidemic and the challenges entailed in implementing a five-year multi-sectoral health policy, this paper aims to strengthen policy implementation by outlining a set of research findings from a qualitative study conducted in 2008 with a group of seventy-six HIV-positive people who access public health services in Khayelitsha, a peri-urban district in the Cape Town metropolis. In response to the NSP's call for research, monitoring and surveillance, this paper seeks to link policy with practice, demonstrating dissonance and convergence between the NSP's stipulated intervention priorities and the key research findings from this qualitative study. The following section outlines the research objectives and methodology for the qualitative study. Thereafter, the paper presents empirical data to reflect on each of the NSP's three priority areas, namely prevention, treatment care and support, and the promotion of human rights and access to justice. In conclusion, this paper develops a set of recommendations that build on the empirical findings of this

study in order to support and inform effective health policy implementation in South Africa.

Research Methodology

This paper is based on a qualitative research project conducted between July and December 2008 with a sub-set of 76 respondents from a panel survey cohort. In 2004 the AIDS and Society Research Unit (ASRU) commenced this panel study with a baseline sample of 242 individuals on HAART and living in Khayelitsha (the HAART Survey). This survey was administered again with the same individuals in 2006 (n = 224) and 2007 (n = 217). For the purpose of comparison with the general population, a control panel survey was conducted with a sample of individuals living in Khayelitsha in 2004 (n = 566), with the second and third waves conducted in 2005 (n = 535) and 2007 (n = 517) respectively. This study is referred to as the Khayelitsha Panel Study (KPS). The quantitative data from the survey points to increased rates of stigma within Khayelitsha, with some respondents experiencing higher levels of perceived and experienced stigma in certain clinics, suggesting the clinic may be shaping the respondents perception and experience of stigma. The particular nature of this relationship – between community, clinic and HIV-positive individual – was unclear and could not be deduced from the quantitative data. For this reason, a qualitative study was developed in order to deepen our understanding of the experiences and challenges faced by a sub-set of respondents living with HIV in Khayelitsha.

The sample for this study was selected from the 2007 HAART survey. In order to probe the nature of stigma and the extent to which it determined the respondent's choice of clinic, we sampled two groups: those who lived in the same geographic area as the clinic they attended (as per the survey data); those who lived in a different geographic area to the clinic they attended[5]. The HAART survey cohort were initially selected in 2004 through a snowball sampling technique, with an aim to trace the impact of HAART on HIV-positive people's lives and to challenge the state's equivocation and delayed provision of HAART through the public sector. As such, many of the respondents

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[5] When we started the interviews, we realised that although this sampling method enabled us to probe whether or not fear of stigma within the community deterred respondents from accessing the clinic closest to their home, the respondents had based their decision to attend specific clinics based on availability of ARVs (initially through the MSF trial).

commenced HAART through the Medicines Sans Frontier HAART trial in Khayelitsha. Given the snowball sampling method, and the gendered nature of health seeking behaviour (cf Beck, 2004; Richey, 2006; Nattrass, 2008; Mills et al, 2009), women are over-represented in the survey sample. In order to balance the gender-ratio of the respondents in the qualitative study, the researchers purposively over-sampled men from the survey cohort. A total of 76 respondents participated in the qualitative study, and each provided at least three sets of information: an in-depth interview; a clinic diary; a clinic map.

The research was conducted in three geographic areas in Khayelitsha determined by the clinics most frequently accessed by the respondents in the survey. In order to explore the connection between the social community and the geographic boundaries of each area, the researchers conducted social mapping with key informants to identify key resources accessed by community members, including faith and community-based organisations (Ingold, 2001). The researchers used participant observation techniques, and spent time 'hanging out' in the waiting rooms of all three clinics; they engaged in informal discussions with clinic attendees, observed the way in which the clinic operated, noted how areas were designated for different 'health needs' and the nature of interactions between clinic staff and attendees. Individual interviews were conducted with each of the 76 respondents, and they were all given a notebook – a 'clinic diary' - in which they could write down their health concerns and experiences of health care. The interview questions were open-ended and semi-structured to allow new and unanticipated perspectives to emerge through the conversation.

Data was collected on HIV testing, disclosure, family and household composition, illness experiences, chronic illness management, sources of support and stigma, perceptions of clinic care and community-based responses to HIV, poverty and unemployment in Khayelitsha. The respondents have all given written consent to participate in this qualitative study. Identifying characteristics of the respondents have been removed from this paper in order to ensure confidentiality and anonymity. Ethical permission to conduct the panel surveys and research with the respondents was obtained through the Universities of Michigan and Cape Town.

Research Findings: From Rhetoric to Reality

This section outlines the NSP's three main policy priorities and presents corresponding findings and recommendations based on the qualitative research project described above. The findings centre on the experiences of a group of HIV-positive respondents and, as such, the findings foreground this particular group's experience of illness and health care in Khayelitsha. The findings are not broadly representative, nor do they seek to draw generalisations across South Africa. Instead, through linking policy with a particular set of research findings, this paper points to a cluster of pertinent findings applicable to HIV-positive people living in areas characterised by endemic poverty and unemployment and it suggests corresponding recommendations based on detailed qualitative research and analysis.

Policy Priority One: Prevention

"It is unlikely that the society will be able to keep up with the demand for health and social services unless there is a significant slowing down incidence of newly infected individuals. This situation underscores the central role and importance of HIV prevention." (NSP, 2007: 59).

By 2011, the NSP aim to reduce HIV incidence rates by 50%. Gender inequality continues to structure South Africa's HIV incidence rates, with impoverished black women almost four times more likely to contract HIV than men of the same age group (Shishana et al, 2005). According to the NSP, a set of tailored interventions are required to reduce HIV incidence, including the acceleration of poverty reduction strategies to create safety nets that support women, girls, orphans and vulnerable children.

In line with the call for tailored prevention interventions, the qualitative research highlights the importance of prevention programs to reduce HIV transmission and re-infection among sero-discordant[6] and sero-positive[7] couples. Both HIV-positive men and women indicated that sexual relationships were sites of struggle as they negotiated disclosure, safe sex and potential stigma with their sexual partners. Women, in particular, described how they struggled to disclose

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[6] This term refers to a sexual partnership in which one individual is HIV-positive and the other is HIV-negative.
[7] This term refers to a sexual partnership in which both partners are HIV-positive.

their HIV status to sexual partners. Women's reluctance to disclose, along with men's reported reluctance to use condoms, reinforced the women's concern about HIV transmission through unsafe sex. For example, Nolungile says,

> "There are things that happen sometimes: like if you are with your boyfriend a condom might break. So you would feel guilty if you have not told him [that you are HIV-positive]... If we have sex without a condom I feel guilty. I think even if I tell him, he would act like he empathizes with you and after that he disappears." (Interview with Nolungile, 2008).

The fear of stigma or rejection following disclosure to their sexual partner combined with a reluctance to use condoms results in un-safe sex that places both men and women at risk of HIV infection and re-infection. Another female respondent described some of the personal anxieties that women share with each other when sitting in the clinic waiting room. In this quote, the respondent also points to the value of shared spaces in clinics, like waiting rooms, that facilitate supportive relationships among the clients:

> "I'll just say, 'People, I have a problem. I don't know what is wrong but I've just developed a rash down below and it's itchy.' We just laugh. And [then] we decide to be serious again and answer one another because we know that this thing is serious and there are people who don't know the role of HIV. So we go deep and teach others and speak about HIV. The one person can contribute their problem and the next will do the same and so forth". (Interview with Mambhele, 2008)

Another female respondent concurs that it is important to disclose one's status to a new partner: "It all depends on a person to tell their partner, 'Yes I love you too, but I live with this virus'." (Interview with Bogie, 2008).

Like Nolungile, however, respondents were concerned that their partner would discriminate against them if they disclosed that they were HIV-positive. Fear of stigma emerged across the interviews, affecting both men and women's decisions to disclose in order to initiate safe sexual practices with their partner. For example, Sipho said that he had wanted to disclose his status to his wife in order to solicit support from her, and to ensure that they practice safe sex. However, he was concerned that she would withdraw her support from him once he disclosed his status. Sipho's fear of stigma was borne out in his wife's response:

> "I decided to tell my wife first.... but it was a very big challenge because I did not get any support from her. I was very disturbed and

felt betrayed after I told her. It even led me to think I shouldn't have told her." (Interview with Sipho, 2008).

Effective HIV prevention programs not only need to target HIV-negative individuals in order to encourage them to protect themselves from contracting HIV: they also need to address the social challenges faced by HIV-positive people in disclosing their status and practicing safe-sex in order to reduce HIV infection and re-infection. Accordingly, HIV prevention strategies should engage a cadre of sero-discordant couples in long-term relationships in order to assess some of the challenges faced by people living with HIV, specifically in relation to sexual and reproductive decision-making (cf Rispel, 2009). Evidence of the lived experiences and wellness management strategies used by discordant couples to reduce the risk of infecting the negative partner can be used to empower HIV positive people to address the anxiety they feel when preparing to disclose their status to a new partner.

Policy Priority Two: Treatment, Care and Support

"The target is to provide an appropriate package of treatment, care and support services to 80% of people living with HIV and their families by 2011 in order to reduce morbidity and mortality as well as other impacts of HIV and AIDS." (NSP, 2007: 59).

This policy priority encompasses a diverse set of goals and interventions to support people living with and affected by HIV. Voluntary counselling and testing (VCT) is the first point towards accessing health care, including HAART, for people living with HIV. Therefore, the NSP aims to establish a national culture in which VCT is encouraged, and to increase VCT services in the workplace and through trade unions. Importantly, the NSP recognises the value of engaging with community-based organisations to develop innovative strategies to promote VCT. After learning their status through VCT, some of the respondents became involved in CBOs to promote VCT and general support for people living with HIV. One of the main strategies proposed by the respondents to promote VCT includes 'door-to-door' campaigns in which trained counsellors visit households, provide information about HIV and offer VCT. According to the respondents engaged in CBOs, this form of provider-initiated testing has encouraged people to test for HIV.

In addition to voluntary and provider-initiated testing services, this policy priority aims to extend health care support to PLWH in order to ensure effective management of HIV as a chronic illness. HAART is a crucial component in the chronic management of HIV. Although HAART is a critical component for managing HIV as a chronic illness, the respondents noted a number of concerns related to health care provision that negatively shaped their experience of care and support within these clinics. Three key and inter-related concerns emerged, highlighting the consequences of limited human and infrastructural resources in the public health system. First, over-stretched health care personnel were unable to give adequate attention to the respondent's health needs. One respondent noted his discontent with clinic staff in a clinic diary entry: "There is no co-operation at the clinic. Nurses don't treat people in a nice way – they get irritated with people." (Clinic Diary, Bongani, 2008).

The second concern also relates to the high demand for clinic care, which results in waiting in long queues for hours before receiving attention. Some respondents leave their house early in the morning, and wait in the queue outside the clinic before the doors open at 07h00. The following quote from a respondent's diary indicates the amount of time entailed in visiting a clinic to receive care:

> "Early in the morning at 4 o'clock I wake up preparing to go to the clinic. I arrived there [and waited] in a queue... The gate opened at 5 o'clock and we queued inside the yard. At 7 o'clock the clinic doors opened and we get inside the clinic. The doctors and nurses arrived at 8 o'clock." (Clinic Diary, Lulama, 2008).

Once inside the clinic, respondents wait for a few hours to see the doctor or nurse, and then again to receive medicine from the pharmacy:

> "So I would say I wait for around 3 hours in that waiting area before seeing my doctor. That excludes the hours I spent waiting outside. Then I have to go to the dispensary and wait for an additional 2 hours for my medication. So my dreams of just quickly popping in and out of the hospital never really materialize." (Interview with Sipho, 2008).

In the interviews, we asked the respondents about the changes they would like to see in their clinics. Some of the respondents suggested that a 24-hour clinic is set up in Khayelitsha to reduce long queue and provide emergency care; other respondents suggested that architects design enclosed areas outside the clinic in which people can stay warm while they wait for the clinic to open in the morning.

A high demand for health care, over-stretched health personnel and limited health resources all negatively affect the capacity of the health system to respond to the treatment and care needs of people affected by HIV. This has ramifications on the health of HIV-positive people. Many of the respondents in the study who are employed, and on HAART, spoke of the difficulties they encountered when attending the clinic for their monthly check up. In order to receive their treatment, they are required to attend the clinic for blood tests, weight checks, and general health monitoring. Their visits generally require them to take a day off work every month in order to accommodate the long queues in the clinic. This places pressure on PLWH as they may lose a day's wages, or they may have to disclose their status to their employer in order to account for their absence from work. Many respondents chose to miss clinic appointments in order to avoid disclosing their status to their employers or losing their wages. A respondent from the study who is also a community health worker states:

> "There are many who have stopped taking their ARVs. Some of them stop taking their pills [because they] are working. So a person will say since I started working I don't have the chance to go the clinic" (Interview with Zuziwe, 2008).

Further, some of the respondents pointed out that their physical health had improved, and explained that this meant that they no longer needed to take ARVs as rigorously as they had when they had initially commenced their treatment. An under-resourced health system, therefore, places strain on HIV-positive clients, particularly when it entails absenteeism within the employment sector. Poor adherence, due to missed clinic appointments, is compounded by a fear of stigma, the loss of earnings, and a belief that resumed health on ARVs warrants a less rigorous treatment program. Fear and experience of stigma within clinics also deters some HIV-positive people from accessing health care services. This is discussed in more detail in the following section on stigma and access to justice – the third policy priority in the NSP.

The respondents reported struggles that extend beyond accessing and adhering to AIDS treatment and, as such, reinforce the NSP's call to address socio-economic factors like poverty and unemployment. Comprehensive care and support, according to the NSP, entails: improving enrolment of HIV-positive people on wellness programs to promote positive living interventions; food support for eligible households; and psychosocial support for disclosure, stigma and bereavement.

The dimensions of poverty reported in the research include poor housing, unsafe water, no electricity and no flushing toilets. One respondent used his diary to record what he had dreamt of during the night. In one entry, he wrote: "Today's dream was that I have a house of bricks with electricity. I was surprised - when I woke up in the morning - that I am still living in this raining shack without electricity." (Clinic Diary, Quma, 2008) Another respondent spoke of her frustration at the lack of toilets: "We don't have toilets: there is also this other place that they call the dump. So these are the things that I can say I hate. Because that place is dirty." (Clinic Diary, Dunyiswa, 2008).

Employment and social welfare are two avenues for ameliorating wellbeing in the face of poverty. HIV illness can be debilitating prior to commencing HAART, and disability grants are awarded for 6 – 12 months to such individuals in order to provide a level of financial stability. Once on HAART, many of these individuals become healthy and because it is possible to re-enter employment, they no longer qualify for the disability grant. However, with high levels of unemployment, many of the respondents reported difficulty in finding work. For example, a male respondent argues that,

"People are struggling out there! And people complain about this government grant that only comes out when person is very sick. So these are the complaints that I hear of there. People say that "I mean I am fat right now but am still struggling! Why do they have to wait until I am skinny for them to realise that I am struggling and hungry or sick?" (Interview with Lungisa, 2008).

Another man said that his main worry in life was, "The fact that I am sitting around and I am not working... There are no jobs here, especially if you are not educated, it not easy to get a job." (Interview with Puleng, 2008). Physical struggles related to HIV, like swollen feet for example, made it difficult for some respondents to search for work. One respondent recorded a diary entry about her search for work during the day. She wrote:

"I wake up early in the morning, wash my hands and eat porridge. After that I take my tablets and went out to look for job, when I am coming back my legs were tired and painful. On the other day I came back with swollen head because I did not find the job at the place I was hoping to get it. Each and every day I wake up going out to look for a job sometimes while I was busy walking my legs became swollen and painful." (Clinic Diary, Hloniphe, 2008).

For some respondents, it was difficult to search for work. Other respondents found it difficult to stay employed because they became sick with HIV-related illnesses, like tuberculosis. One respondent said,

> "Before I had the virus I was a worker – I used to be a farm worker since I didn't have any schooling... I first became sick in 1998 and I was working at some tomato farm back then... I stopped because I became sick and was attacked by TB." (Interview with Baleka, 2008).

Similarly, another respondent recalled getting sick so frequently that his employer started to question him and encourage him to test for HIV:

> "I never really stayed long in that job because of my ill-health... I constantly had fights with my contractor/employer and he would ask, 'Why are you always getting sick every month?"[This] led me into deciding on getting tested for HIV." (Interview with Sizwe, 2008).

There are a range of consequences of unemployment and poverty on the health and wellbeing of HIV-positive individuals. Poor ventilation in informal settlements, for example, increases risk of tuberculosis infection for HIV-positive individuals and members of their household. Inadequate nutrition undermines the general health of HIV-positive people and reduces the efficacy of AIDS treatment. A key aspect of the NSP's second policy priority entails collaborative engagement across government and civil society in order to support people living with HIV.

In Khayelitsha, the respondents spoke of successful projects that link government services through the clinic with non-governmental services in the community. Some of the respondents entered in to training programs with NGOs and subsequently worked in clinics and other organisations to support people living with HIV. In conversation with Thobani, Sipho explains how learning of his HIV status gave him access to a range of support through NGOs:

> Thobani: So how does living with HIV affect your life?
>
> Sipho: It affected it a lot before I knew my status. But now that I know [I'm HIV-positive] my life isn't affected that much because I now have knowledge that I gained. I was trained by Yabonga. I was trained by the TAC (Treatment Action Campaign). I was trained by Wolanani. I was also trained by HOPE Worldwide. So I have a lot of expertise to withstand all of the challenges that might approach me. I am well equipped to fight my battles.

In line with the NSP's call for integrated care and support for people living with HIV, the respondents assert the importance of addressing contextual factors, like poverty and unemployment, because they limit the extent to which they can achieve and sustain health on AIDS treatment. Unemployment is exacerbated by the physiological ramifications of HIV illness, which makes it difficult for some people living with HIV to seek and then sustain employment. On the other hand, even when healthy and able to work, the employment market is heavily saturated and therefore unable to offer jobs to many of the HIV-positive respondents. The ramifications of poverty and unemployment undermine the respondents living conditions and negatively affect the quality of housing and access to basic services like good sanitation, electricity and clean water. Therefore, these findings highlight the importance of integrating a multi-sectoral response to delivering care and support to people living with HIV through creative and comprehensive collaborations that link government departments with civil society organisations working in under-resourced areas like Khayelitsha.

Policy Priority Three: Human rights and Access to Justice

"Respect for and the promotion of human rights must be integral to all the priority interventions of the NSP. In addition, active and ongoing campaigns that promote, protect, enforce and monitor human rights must be linked to every intervention and mounted at district, provincial and national level." (NSP, 2007: 60)

HIV highlights some of the most serious human rights fissures within South Africa's social, political and economic fabric. Accordingly, the NSP calls for increased awareness and sustained interventions to address HIV as a human rights issue, particularly in relation to stigma, gender inequality and orphans and vulnerable children. Through concerted interventions to promote this policy priority, the NSP aims to mobilise society to promote gender and sexual equality, address gender-based violence, promote knowledge of and adherence to legal rights, and to build a cadre of HIV-positive people in order to address stigma and discrimination.

The findings from this research project connect primarily with HIV-related stigma as a dimension of human rights. The respondents noted a marked

reduction of stigma within their households and families, but continued to experience consistent levels of stigma within their social and geographic community. Fear and experience of stigma within the community has deterred some HIV-positive individuals from accessing health care from their local clinic; instead, they travel some distance to receive medical care from clinics further away from them in order to avoid possible disclosure of their status to members of their community. This section outlines the dynamic nature of stigma and support as reported by the study respondents, and suggests that a cadre of HIV-positive leaders are emerging, as per the NSP's aim, to support HIV-positive people and challenge HIV-related stigma in Khayelitsha.

The articulation of stigma ranges from overt discrimination like verbal or physical maltreatment to covert actions, like spreading rumours about individual's HIV status. Thozama, for example, lost sight in one eye due to HIV. In her diary she wrote about feeling stigmatised due to her damaged eye:

"A day that was painful... On the way from buying electricity I met with girls. They upset me and I was hurt... One of them laughed and said, 'Hello Auntie! ... What happened to your eye?' I cried and my heart was painful." (Clinic Diary, Thozama, 2008).

A young male respondent, Menzi, described how HIV-positive people are maligned as 'other', and stigmatised not only because they are viewed as socially deviant, but also because their HIV-status is a negative reflection on the broader community in which they live. This points to the dynamic nature of illness as affecting both the individual and also their social environment, thus reinforcing the value of engaging with illness as both social and physiological (cf Kleinman, 1995), and the way in which these dialectic relationships compound stigma:

"When you live with HIV there is still that [idea] that people living with HIV aren't recognised as people. They are looked upon as people who self-inflicted HIV on themselves or as people who tarnish the community's image. And as you can see in the newspapers, there are court cases and stories of people being killed because they have HIV. You find that if you get caught or seen wearing a t-shirt with 'HIV' written on it, you will become a target because you are tarnishing or dirtying the community. It's as if people living with HIV here in Khayelitsha aren't human beings." (Interview with Menzi, 2008).

Unlike the respondents above, Sipho recalls positive treatment in the community compared to initial stigmatising treatment within his family:

> "In my community they never labelled me as anything. I had it in my family at times that they would say things such as, 'Don't use that mug he used!' You see? 'Don't use that spoon he was using!' And so there was just a little bit of misunderstanding in those regards and I tried to show them that this thing does not get spread by kissing or using same things." (Interview with Sipho, 2008).

Another respondent spoke of a positive reduction in stigma; she suggested stigma reduced as more people who were open about their status to members of their family and community: "What made them change is that ... the HIV virus was rising. Those people they're pointing at are usually get better." (Interview with Ngoza, 2008).

The respondents' experiences of stigma within their community compounded their fear of stigma when accessing community health resources, particularly local clinics. Accordingly, fear of stigma deterred respondents from accessing health care through their local clinic, and prompted them to travel outside their community to a distant clinic. After discussing his own experiences of stigma, Sipho went on in the interview to explain why other people chose to access clinics that are not within the vicinity of their homes:

> "A person will say 'I don't want to go to the clinic in which I am known because I will get seen by people who know me there and notice I am waiting in the HIV section. I was seen waiting there for my HIV treatment, and even though I wasn't ready to tell my family yet, that person who saw me there will have already spread the news." (Interview with Sipho, 2008).

Other respondents concurred, saying that because they were a teacher, or a leader in the community, they did not want to inadvertently disclose their status to members of their community in their local clinic. Nomawethu wrote in her diary that "people are attending far clinics because they are still in denial and there's stigma in their communities." Similarly, Baleka wrote about finding out that her aunt was HIV-positive because she met her in her local clinic waiting to see the doctors who cared for PLWH. The aunt told Baleka, "Don't you dare tell my sister that you met me at the clinic today." Thereafter, Baleka's aunt moved to another clinic and refused to have further contact with her.

Zuziwe, a female health worker notes a similar trend:

> "There are people, some are running away from the stigma of their community others don't want to seen that he or she comes to this

clinic so they go to this clinic so he rather go to Cape Town so that he won't be seen." (Interview with Zuziwe, 2008)

But, like Sipho above, Zuziwe never felt that she needed to change clinics. She said, "I never had a problem to go to the clinic in my community because I thought that this would motivate other people". (Interview with Zuziwe, 2008).

Stigma, therefore, has a range of ramifications on the respondents' lives, particularly in relation to family relationships and experiences of discrimination within their social community. Fear and experience of stigma within the social community deterred HIV-positive people from accessing health care from their local clinic, which indicates that further research is required to develop a set of strategies to reduce stigma within communities, and to encourage people to access health care timeously through their local clinic.

There are areas within the clinic that are designated for people in need of particular treatment for tuberculosis and HIV. As described above, some respondents are reluctant to be seen in these parts of the clinic because they fear inadvertently disclosing their HIV status to members of their community. However, the respondents also spoke about the support they receive from engaging with other people who are also waiting in the same area for their monthly check-up or to receive antiretroviral treatment. Thandiwe, for example, spoke about the support she receives when sitting in the 'HIV waiting area' of the clinic. In the quote below, Thandiwe describes certain 'sides' of the clinic in which people wait to receive particular kinds of treatment:

"So we will be sitting and someone will come in and ask, 'What is this side for?' And we will then ask them 'what side are you looking for?' That person will not want to say it, and it turns out that person is also coming to this side [because they're HIV-positive] but they're just scared to say so. So we usually talk about things like that and we usually just say people who are still scared of such things shouldn't be scared of such, because it is now common. And we support one another." (Interview with Thandiwe, 2008).

Others spoke of the discomfort some HIV positive people feel when sitting on the HIV side because of the identifying features such as information leaflets and posters. A male respondent spoke about some acquaintances he met in the clinic,

'They are just shocked to see me there as well. You will see someone on one day only and then you never see them coming back again. Then you later hear that they passed away because they were busy

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running away from people in the community. So they kept hiding and when they see you at the clinic, knowing you, they will think that you will go around talking about them…you are also there for your own problem. You see? …In actual fact they are taking away their own lives". (Interview with Kagiso, 2008).

Conversely, sitting in areas designated for PLWH also provides scope for mutual support amongst the clinic patients. Nozipho described her experience of sitting in the waiting area for HIV-positive people: "The things that they mostly talk about is this HIV and their CD4 counts... You'll find that people boast about their CD4 counts as if a person has won the lotto – once their CD4 count is high they become very proud! (Interview with Nozipho, 2008).

An important finding from this qualitative research relates to changes in stigma over time. Quantitative research on the survey dataset have illustrated that the respondent's experience and perception of stigma has increased over time (see Maughan-Brown, 2008). This qualitative research suggests, however, that the sub-sample of the survey respondents notes a decline in overall stigma. The respondents attribute this shift in stigma to an increased awareness of the prevalence of HIV, the value and efficacy of HAART, and the acknowledgement that HIV infection affected too many sectors of the population to validate the link between infection and moral degeneration. As Noluvuyo says,

"When HIV emerged it was very bad because someone with HIV was perceived as misbehaving and sleeping around with anyone. Then HIV became common, so now people are no longer talking bad about someone who is HIV positive, I have not heard anyone saying bad things to someone I know." (Interview with Noluvuyo, 2008).

Leadership and support are crucial components in challenging HIV-related stigma in South Africa. Support groups played an important role for the respondents as they adjusted to living with HIV, and to taking antiretroviral treatment. The development of a cadre of HIV-positive activists and leaders in Khayelitsha emerged from the study, and suggests that new communities of support have been formed among people living with HIV. Demonstrations of strength through solidarity confront stigmatising attitudes and behaviour, particularly when HIV-positive people engage with members of their community to provide education around HIV prevention and treatment. For example, Sipho describes his role in the community below:

"Well, here in my community right now, I'm like a soldier that is fighting for his nation. In the sense that I now know my status and I

wouldn't like to see other people getting infected with HIV. So now I defend and also impart education ... I give people advice and education on HIV." (Interview with Sipho, 2008)

As described in the quote above, Sipho plays an active role as a leader and educator in his community and clinic, and his ability to transform his HIV status in to a positive dimension of his life was facilitated through his support group:

"A lot of advice from withstanding this HIV virus came from my support group. Those people made me very strong and built my future... The support group made a huge impact on the shocking news that led me to think I would never be human again. When I met with the support group I met other people who were living with the virus for a number of years... I was strengthened. These support groups have given me a lot of emotional support and health." (Interview with Sipho, 2008).

The findings presented above indicate that stigma continues to shape HIV-positive people's lives. Under the section above detailing the policy and research findings around HIV prevention, the findings pointed to the negative effect of stigma on disclosure within sexual relationships. This section suggests that fear of stigma within communities deters people from accessing health care from their local clinic. In addition to the negative effects of stigma on the lives of HIV-positive people, the research findings also indicate that stigma is shifting as HIV becomes more 'common' and as people see the positive effects of HAART on HIV-positive people's health. Further, communities of support and leadership are emerging within Khayelitsha to provide education and challenge stigma around HIV, thus connecting to NSP's goal to mobilise society and build a human rights framework to support people affected by HIV within South Africa.

Recommendations and Conclusion

With a population of just over 5.5 million HIV-positive people, South Africa's national health policy response is of critical importance for improving human development outcomes in line with the MDG to halt and reverse the HIV epidemic (UNAIDS, 2008). The section above presents three key priorities within the national health policy document, and draws out key research findings from a qualitative research study to highlight areas that require further support in order to meet the objectives laid out in the NSP. Although critics of the NSP concur with the key priority areas outlined in this paper, they also point to

persistent weaknesses across the old plan and the current five-year policy. For example, Venter (2007) notes that South Africa is applauded for producing rigorous policy papers, but that it fails to transform policy in to meaningful practice through targeted interventions. In line with this critique, this section contrasts the policy rhetoric with the findings from our empirical study, and develops a corresponding set of recommendations to enhance the implementation of South Africa's national health policy.

The first policy priority aims to reduce HIV incidence in South Africa by 50% between 2007 and 2011. Women's vulnerability to HIV infection requires concerted intervention strategies that promote women's rights, and engage with both men and women to reconfigure oppressive gender dynamics. In the research findings, fear of stigma and rejection within sexual relationships discouraged men and women from disclosing their status to their sexual partner (Cf Almeleh, 2006; Skhosana et al. 2005; Skhosana et al. 2009). Combined with unsafe sexual practices that prohibit condom use, both men and women are vulnerable to HIV infection and re-infection through unsafe sex. The findings from this study therefore recommend that effective HIV prevention programs should not only target HIV-negative individuals: they also need to address the social challenges faced by HIV-positive people in disclosing their status and practicing safe sex in order to reduce HIV infection and re-infection

Under the second policy priority, the NSP aims to reach 80% of all South Africans in need of treatment, care and support by 2011. The findings reinforce the NSP's recommendation to work with non-government organisations to promote VCT and create a 'culture of testing' in South Africa. The human resource crisis within the health system affected the respondents' experience of health care provision in Khayelitsha. Health care personnel were over-stretched and respondents indicated that their engagement with clinic staff felt rushed, impersonal, and that the distribution of tasks across health personnel was poorly coordinated within the clinic

In line with the findings from this study, MSF (2008) notes that there is a chasm between the stipulated goals in the NSP and the practical outcomes of the Department of Health's Human Resource Plan for HIV/AIDS care delivery. The rapid roll-out of ARVs has placed enormous pressure on under-resourced clinics and, given the scale of the epidemic the pressure on the health system will increase rather than abate (cf Fassin, 2008). Clinics need to double the initiation of patients on ARVs from 200,000 to 420,000 individuals per annum in order to

scale-up the ARV roll-out in line with the NSP's goal of 80% coverage by 2011 (MSF, 2008; Hirschhorn & Newell, 2007; Venter, 2007).

A key intervention for addressing the human resource crisis within the health system, as espoused by the NSP, relates to task shifting, or the reallocation of tasks across clinical and lay health practitioners. To date, ARV services in South Africa have been primarily doctor-led and hospital based; proponents of task shifting recommend that nurses diagnose and treat opportunistic infections, and initiate and monitor patients on ARVs (MSF, RHRU, Southern African HIV Clinicians Society, TAC, 2009). Further, the NSP recommends that lay counsellors are trained to administer HIV rapid tests (currently only administered by nurses) and that pharmacy assistants are enabled (and supervised) to dispense ARVs. The value of task shifting lies in creating more points of care within the health system and closer supervision of PLWH on ARVs, as demonstrated by the MSF program in rural Lusikisiki.

Countries like Malawi, Lesotho and Mozambique have demonstrated the efficacy of task shifting within the public health system, and subsequently amended regulatory guidelines to enable task shifting at a national level. South Africa, however, has failed to initiate the same process within the public health system. Task shifting requires political backing from cabinet and from SANAC, and entails coordination across national, provincial and local government to clarify directives for nurse-based initiation and management of ARVs. In line with facilitating and coordinating task-shifting at a national level, proponents call for expedited legislative transformation, driven by the South Africa Nursing Council, to provide scope for nurses to initiate and manage ARV programs. Similarly, the South African Pharmacy Council has been called on to enable pharmacy assistants to dispense ARVs (MSF, RHRU, Southern African HIV Clinicians Society, TAC, 2009).

The respondents noted the impact of the human resource crisis on the level of care they received within the clinics. Some respondents expressed their frustration at waiting many hours to see the doctor or the nurse, and then having a very short consultation in which to raise their concerns; they also felt that their health concerns had not been adequately addressed by the clinic staff during their consultations. 'Depersonalised care' of patients by nurses was also observed by Van der Walt & Swartz (2002) in a TB control programme at a primary health care centre in Cape Town. The researchers concluded that the nurses' attitudes were negatively influenced by task shifting as it placed greater pressure on nurses to manage a wider range of tasks and a heavier workload,

without corresponding financial compensation. In order to address 'depersonalised care', an education intervention was developed and evaluated by Dick et al (2004); the study demonstrated that although the intervention was well received by the health practitioners, financial and infrastructural limitations constrained the extent to which the program could be implemented and sustained. In their evaluation of task shifting in primary health care centres in the Free State Province, Zachariah et al (2008) also found that task shifting may not be welcomed by various health professionals. Doctors and pharmacists objected to their work being done by 'half-baked doctors', and nurses objected to doing doctor's tasks without corresponding remuneration. Further, professional representative councils raised concerns over delegating tasks to lower level professionals (Zacharia et al., 2008).

In addition to infrastructural and human-resource limitations within the public health sector, social factors, like stigma, also deterred some respondents from accessing health care resources through their local clinic. Demarcated areas within the clinic may inadvertently disclose an individual's HIV status; this deters some HIV-positive people from attending their local clinic, and instead they travel to a clinic that is further away in order to avoid potential stigma. This finding parallels ethnographic findings from a study of home-based care practices in Nyanga: HIV-positive clients refused to access the local health clinic because they feared stigma from the health personnel and from other members of their community (Mills, 2006). 'Safe spaces' within clinics can be created through integration of a range of services that promote biomedical care, psycho-social wellbeing and information to engender a supportive environment within the clinic and to dispel the risk of disclosure when accessing specific services within areas delineated for HIV-positive people (cf Rotherum-Borus et al, 2009). This enters in to a larger debate around secrecy, disclosure and stigma. Stigma may be reduced through a more open and frank discussions about HIV within and beyond clinics; conversely, efforts to cast HIV as deserving of secrecy may propel stigmatising attitudes towards HIV as 'other' (Norman et al., 2005; Lane, 2009). The respondents noted that a greater level of awareness of the prevalence of HIV within families and communities had reduced pernicious experiences of stigma. Further, they also noted that the conversations they had while waiting to be attended in the clinic had improved their knowledge around STIs; these discussions also created scope for kindness and support among people living with HIV who may or may not have known each other prior to accessing care through the clinic. Further research is required to understand the way in which the clinic space structures social relationships

and may fuel stigma or promote support among members of the communities accessing health services.

In addition to providing basic health services, the NSP notes the importance of ensuring general wellbeing for people affected by HIV. This includes psychosocial support, access to wellness programs, food parcel schemes and support groups. The respondents from this study highlight the importance of understanding HIV in the context of intransigent poverty and high levels of unemployment. The causal relationship between well-being and development is bi-directional, and the cases above indicate that economic growth is not a necessary or sufficient factor in promoting the health of a country's citizenry. South Africa's economic development is layered; the findings presented above suggest that entrenched and endemic levels of socio-economic inequality negatively constrain the ability of PLWH to secure and sustain well-being, even with public provision of ARV treatment. Economic growth has been relatively positive, but it has not been accompanied by sufficient growth in employment to address South Africa's very high rates of unemployment (Seekings and Nattrass, 2006). Unemployment exacerbates poverty and undermines the health of HIV-positive individuals; in turn, HIV illness prohibits people from seeking or sustaining employment. In this study, the respondents noted that illness significantly undermined their ability to seek employment and, consequently, some were able to qualify for a disability grant. Resumed health, however, presented new challenges to the respondents as they no longer qualified for disability grants, and yet were either unable to find employment or struggled to find suitable employment conditions that would accommodate their illness. Studies documenting employment patterns among PLWH on ARV treatment parallel the findings from this study, noting similar difficulties faced by PLWH when returning to work (Nixon and Renwick, 2003; Ezzy, de Visser and Bartos, 1999).

Given these findings, this paper recommends strategic creation of employment programs particularly through community-based organisations, development of employment policies that support rather than stigmatise HIV-positive individuals, and a strengthening of the national welfare system to support people who are unable to work through the provision of disability grants. Similarly, Blankenship et al (2006) and Porter et al (1999) reinforce the importance of structural interventions to curb the debilitating impact of HIV/AIDS.

The third policy priority addresses the human rights dimension of HIV in South Africa, and calls for the mobilisation of communities to challenge HIV-related

stigma and promote equality, particularly in relation to women's rights. The respondents note that there has been a general decrease in their experience of stigma, particularly within their family and household. They attribute this change to a number of factors including: a broad social recognition that HIV affects many people, and is not aligned with social deviance or immorality; the positive and transformative impact of ARVs which has reinforced the understanding that HIV is a chronic illness and not a precursor of imminent death.

Experiences of persistent and pernicious stigma within the community contrasts with the respondents' experience of a decrease in stigma within their families. Further, and as discussed under the first policy priority, the respondents noted significant concerns about stigma within their sexual relationships. As such, stigma is detrimental to the health of HIV-positive individuals because it discourages men and women from disclosing their status to their sexual partner, and it also deters them from accessing health care through their local clinic (Kalichman, 2003; Mills, de Paoli and Groeningstaeter, 2009). To this end, this policy paper recommends that HIV awareness programs focus attention on 'sexual health interventions to support men and women within sexual relationships, and to create 'safe-spaces' within clinics where HIV-positive people can receive treatment without risking potential disclosure of their status to their community.

The respondents also iterated the value of support groups and local community-based organisations (CBOs), and derived a significant deal of emotional support from participation in CBOs and support groups. The use of CBOs and NGOs in HIV/AIDS care management is connects with the task shifting debate. While it is a good strategy to strengthen community involvement, and health care services, strategic implementation and allocation of task is paramount. Michaels and Eley (2007) argue that lay workers in the Western Cape play an important role in counselling, education and treatment adherence support within primary health care settings. However, they are employed on contract basis by NGOs and CBOs and, therefore, the nature of employment does not guarantee long-term service delivery in primary health care centres (ibid). Furthermore, the uneven standard of practice within NGOs and CBOs, disparate training requirements and poor remuneration calls for critical consideration of their inclusion in public health care. This paper, therefore, recommends that government departments work more closely to support CBOs and coordinate health care interventions to enable rather than exhaust the capacity of CBOs to

respond to the health needs of HIV-positive people living in under-resourced areas like Khayelitsha.

The NSP is a comprehensive policy that aims to curb the impact of HIV and AIDS on South Africa, but the extent to which rhetoric is translated in to action is strongly determined by the multi-sectoral coordination at a national, provincial and local government level. Further, non-governmental organisations play a crucial role as implementing agencies of the NSP and as such require extensive support and coordination through SANAC. Broader contextual issues that impede the successful implementation of policy also require close attention and further research; the extent to which the HIV-positive research respondents were able to derive the benefits of resumed health on HAART was also affected by economic and social factors like poverty, unemployment and stigma. The findings presented above therefore reinforce the importance of addressing South Africa's HIV epidemic across government and civil society, with a particular focus on vulnerable population groups and with a recognition that lived experiences of HIV-positive people in South Africa continue to be structured according to entrenched inequalities that require institutional and infrastructural redress.

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