The people living with HIV stigma index

An index to measure the stigma and discrimination experienced by people living with HIV in South Africa

11/26/2014

Submitted by the Human Sciences Research Council (HSRC) to the South African National AIDS Council (SANAC) on behalf of the SANAC People Living with HIV (PLHIV) Sector
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Background

Introduction

Stigma against people living with HIV (PLHIV) remains one of the central barriers to effective prevention and management of HIV in Africa (Leclerc-Madlala et al. 2009; UNAIDS, 2012). Stigma and discrimination associated with HIV are universal, occurring in every country and region of the world (Deacon et al. 2005). PLHIV are often abused, rejected and negated. People infected with HIV often hide their status to partners for fear of rejection and abuse. Stigma and discrimination towards PLHIV is widely recognized as a barrier to the provision of adequate health care, adequate psychological and social support, and appropriate medical treatments (LeClerc-Madlala et al. 2009). The major consequences of stigmatizing behaviours include prejudice, discounting of others, and discrimination directed towards individuals perceived to have HIV (Deacon et al. 2005). Discrimination is said to occur when people are singled out in a way that results in them being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Discrimination against an HIV-positive individual is one form of violating that person’s human rights (UNAIDS, 2012).

Stigma and discrimination towards PLHIV manifests itself in two main ways (Deacon et al. 2005). In the first instance, external stigma (enacted by others towards them) includes acts of prejudice and discrimination towards those with the stigmatised identity. Secondly, internal stigma or self-stigma (self-defacing internal representations felt by PLHIV) refers to the assimilation and internalization of the socially constructed views of AIDS held by people living with HIV. Moreover, even with the advent of long term treatment for HIV in terms of antiretroviral treatment (ART), many PLHIV still do not disclose their HIV positive status to family, friends and sex partners for fear of discrimination, victimization and rejection (LeClerc-Madlala et al., 2009; UNAIDS, 2012). Hence, unless HIV and AIDS-related stigma is better understood it will continue to be a serious barrier to HIV testing as well as prevention, treatment and care for PLHIV and also the mitigation of impact of the disease in South Africa. The South African National Strategic Plan of HIV and tuberculosis aims to address and ascertain the levels of stigma in South Africa (DOH, 2012).

Acts of prejudice and discrimination directed towards PLHIV is widely recognized as a barrier to accessing HIV prevention, treatment, care and support (UNAIDS 2012). However, it is likely that self-defacing internal representations of being a PLHIV is an important predictor for long-term adjustment and coping with HIV infection. Data collected among 1068 PLHIV from Cape Town in South Africa, 1090 PLHIV from Swaziland and 239 PLHIV from Atlanta in the United States of America (USA) reported that internalized stigma was positively correlated with depression scores in all three countries, higher internalized stigma scores were related to greater depression symptoms (Kalichman et al., 2009; Simbayi et al., 2007). For participants in both Cape Town and Atlanta, individuals who indicated that they have been treated differently since disclosing their HIV status endorsed significantly greater internalized stigma. For all three cities, individuals who indicated that they have not discussed their HIV status due to fear of the consequences of disclosure endorsed greater internalized AIDS stigma (Kalichman et al., 2009). In a study conducted among 92 HIV positive men who have sex with men (MSM), in Cape Town, South Africa, internalised stigma was high among all HIV positive men who took part in the survey, with 56% of men reporting that they concealed their HIV status from others (Cloete et al., 2008). HIV-positive MSM reported experiencing greater social isolation and discrimination resulting from being HIV-positive, including loss of housing or employment due to their HIV status.

In a South African national household survey of 2002, 26% of respondents indicated that they would not be willing to share meal with a person living with AIDS, 18% were unwilling to sleep in
the same room with someone with AIDS and 6% would not talk to a person they knew to have AIDS (Shisana & Simbayi, 2002). Hence in this study, a substantial proportion of the sample reported negative attitudes towards PLHIV. In a 2005 survey (Shisana et al., 2005), an overwhelming majority of people indicated that they would be willing to care for a family member with AIDS. However, varying proportions of respondents showed some degree of negative attitudes and perceptions in relation to PLHIV. Respondents indicated some hesitance about marrying a person with HIV and AIDS, with less than half (46.5%) indicating that they consider doing so. Deacon et al. (2005) suggests that it is vital to distinguish between negative things people believe about HIV and AIDS and PLHIV and what we should call discrimination (what people do to unfairly disadvantage people living with HIV and AIDS). In fact, according to Deacon et al. (2005), stigma does not always have to result in discrimination to have a negative impact, because people may internalize stigma or expect to be stigmatised or discriminated against, and may not come forward for testing or treatment, or enjoy a good quality of life as a result. Discrimination can result from stigma but could also stem from resource concerns, fear of infection, racism, sexism, and so on.

In Africa, various human rights violations have been reported, such as sexual abuse and coercion, discrimination in access to health information, discrimination in property inheritance, rape and labour exploitation (Human Rights Watch, 2003 & 2004 cited in Ndinda et al., 2007). HIV and AIDS-related stigma is said to be frequently layered over other forms of social inequalities such as race, gender, class, sex work, homosexuality, religion, xenophobia, transgender, drug use, mental and/or physical disability, caste, disease, and so forth (Deacon et al., 2005; Petros et al., 2006). In the context of HIV and AIDS-related stigma, blame is often assigned to black people or to women. Often, HIV and AIDS-related stigma involving “othering” (blaming and stigmatising the “other” whereas the “other” is defined as someone with a different religion, ethnic group to one’s own, and gay men for the spread of HIV). This accentuates both the exclusion and devaluation of PLHIV leading to double or multiple stigma (“super-stigmatisation”) (Cloete et al., 2010; Petros et al., 2006). Due to existing discrimination against women in various societies, attitudes towards those who get infected are often less accommodating compared to the attitudes towards men in the same situation. Infected women are often blamed for infecting their husbands and unborn children and are described in stigmatising terms such as ‘vectors’, ‘diseased’ and ‘prostitutes’, terms that are rarely used when describing infected men (LeClerc-Madlala et al., 2009). The People Living with HIV Stigma Index is a joint initiative of several organisations who have worked together since 2005 to develop this survey. These include the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. The survey aims to collect information on stigma, discrimination and the rights of PLHIV that will help in advocacy efforts. To date, over 50 countries from all parts of the world have undertaken national surveys using the People Living with HIV Stigma Index (see The People Living with HIV Stigma Index, 2014). Many of these studies have reported that significant minorities in most countries report that PLHIV have experienced physical violence, exclusion from family activities, denial of health care, or lost their jobs or income because of their HIV status. In addition, PLHIV in many countries also have internalized HIV and AIDS stigma with many of them reporting that they feel ashamed of being HIV-positive.

Three NGOs belonging to the South African National AIDS Council (SANAC) PLHIV sector, namely, the National Association of People Living with HIV and AIDS (NAPWA), the Treatment Action Campaign (TAC) and the Positive Women’s Network (PWN) have been helping to implement the survey in all nine provinces of South Africa in collaboration with the HIV/AIDS, STIs and TB (HAST) research programme based at the Human Sciences Research Council (HSRC) and UNAIDS have provided technical assistance.
Why did we conduct the Stigma Index Study in South Africa?

It has long been recognized that action is needed to address HIV and AIDS related stigma and discrimination. By implementing the PLHIV Stigma Index within a country, evidence can be obtained so as to:

(i) Measure and quantify the levels of stigma and identify contributing factors to stigma

(ii) Inform the development and implementation of national policies that protect the rights of PLHIV; and

(iii) Shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content.

However, the benefits of the index, particularly for those conducting it, go further than just collecting this much needed evidence. The People Living with HIV Stigma Index is a project that has been developed and is implemented by and for PLHIV. The process of implementing the index is intended to be an empowering one for PLHIV, their networks and local communities – a critical ingredient for ensuring that the Greater Involvement of People Living with HIV and AIDS (GIPA) principal is renewed.

It is hoped that the index will foster change within communities as it is being used, as well as being a tool to advocate for the broader changes needed according to the index data. Ultimately, it is hoped that the index will be a powerful advocacy tool that acts to support the collective goal of governments, community-based organisations, activists and people living with HIV alike to reduce the stigma and discrimination linked to HIV.

Finally, according to the 2007-2011 National Strategic Plan mid-term review, the priority area – “strengthen implementation of the access to human rights and justice priority area” – needed greater attention, including the development of indicators that measure progress towards reducing HIV and AIDS stigma, discrimination and the impact of gender based violence on HIV infection in women (DOH, 2012) and hence the present study.

Overall aim

The primary aim of the survey was to measure the stigma and discrimination experienced by PLHIV in the general population, and to explore how this information could be used to strengthen interventions programmes and service delivery.
The PLHIV sector, their role, responsibilities and involvement in the Stigma Index Study

**a. Ensuring the greater involvement of PLHIV in the implementation of the Stigma Index**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Achieved/or not?</th>
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<tbody>
<tr>
<td>The SANAC PLHIV sector will provide a list of institutions that provide services for PLHIV for sampling purposes.</td>
<td><strong>Achieved</strong></td>
</tr>
<tr>
<td>- The list should include organisations for PLHIV or attending health facilities and for the purposes of accessing support or care related to HIV and AIDS, linked to an organisation from 18 districts.</td>
<td>NAPWA, TAC and PWN provided lists of support groups that were endorsed by these three organisations.</td>
</tr>
<tr>
<td>1. Western Cape Eden, TAC Cape Metro, NAPWA &amp; TAC</td>
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<td>2. Northern Cape Pixley ka Seme &amp; John Taolo Gaetsewe, NAPWA</td>
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<tr>
<td>3. North West Ngaka Modiri Molema &amp; Dr Kenneth Kaunda, NAPWA</td>
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<tr>
<td>4. Eastern Cape Buffalo City &amp; OR Tambo District, NAPWA &amp; TAC</td>
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<tr>
<td>5. Gauteng Sedibeng: PWN Tshwane: TAC, NAPWA, PWN</td>
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<tr>
<td>6. Free State Mangaung, Thabo Mofutsanyane, NAPWA &amp; TAC</td>
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</tr>
<tr>
<td>7. Limpopo Vhembe &amp; Waterberg, NAPWA &amp; TAC</td>
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</tr>
<tr>
<td>8. Mpumalanga Gert Sibande &amp; Ehlanzeni, TAC &amp; NAPWA</td>
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<tr>
<td>9. KZN uMgungundlovu &amp; UMkhanyakude, NAPWA, TAC, PWN</td>
<td></td>
</tr>
<tr>
<td>Indicator</td>
<td>Achieved/or not?</td>
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<td>--------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>A service provider that is openly living with HIV with the necessary skills will be appointed to translate the stigma index tool in the different languages.</td>
<td>Not achieved</td>
</tr>
<tr>
<td>Due to PFMA requirements, a provider was sourced through HSRC’s SCM instead.</td>
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<tr>
<td>Two PLHIV currently employed by TAC and NAPWA which are the largest of the four organisations of the SANAC PLHIV sector will be appointed as project managers.</td>
<td>Achieved</td>
</tr>
<tr>
<td>Two project managers were appointed, they are representatives of TAC and NAPWA, and they have been employed by the HSRC since July the 14th 2014. They will be employed for the duration of the project. This will include the data analysis and report writing phases as well.</td>
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<tr>
<td>In order to implement the Stigma Index, a total of 90 interviewers will be appointed for 2 months each. Interviewers will all be PLHIV from the PLHIV sector and their networks.</td>
<td>Achieved</td>
</tr>
<tr>
<td>124 PLHIV were employed and are members of PWN, NAPWA or TAC.</td>
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<tr>
<td>Four data capturers will be appointed for 3 months each to learn about data capturing and they will also be from the PLHIV sector and their networks.</td>
<td>Achieved</td>
</tr>
<tr>
<td>Four data capturers (1 from PWN and 3 from TAC) were appointed and received training to do checking and data capturing.</td>
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<tr>
<td>Before fieldwork started the data capturers were involved in fieldwork preparatory activities.</td>
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<tr>
<td>They have been placed under the supervision of the Stigma Index data quality assurance manager. The four data capturers together with the data quality assurance manager established a data management system at the Pretoria office. All data capturers have been trained in using the questionnaire tracking system.</td>
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<tr>
<td>In terms of project management, data collection, data capturing and report writing, all candidates for the above-mentioned roles will be trained in a 3-day workshop by researchers at the HSRC and in collaboration with WRHI¹.</td>
<td>Achieved</td>
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<td>A training programme was developed in collaboration with Pierre Brouard of the Centre for the Study of AIDS, Rob Hamilton (now with PATH), Busi Tshabalala of PWN and other steering committee members.</td>
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<tr>
<td>The training manual was adapted for use in the study.</td>
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<tr>
<td>All fieldworkers underwent a 5-day training of the Stigma Index from the 11th to 14th of August 2014.</td>
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¹ Unfortunately, WRHI researchers have not been involved in the project at all as was originally agreed.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Achieved/or not?</th>
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| • The training was conducted collaboratively with Rob Hamilton from PATH, Pholokgolo Ramothwala of Positive Convention as well as Busi Tshabalala from PWN.  
• Training in terms of the ethics of research and the overall implementation of the study was conducted. | Achieved  
While some few logistic problems such as making sure the diet was appropriate for PLHIV on ARV treatment or providing allowances for food timeously were experienced which caused some unhappiness among some of the PLHIV who were undergoing training, the training itself went very well indeed. |

**b. Ensuring that the process of implementing the Stigma Index is an empowering one for PLHIV**

**The role, relationship and responsibility of HSRC/SANAC/WRHI**

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<tr>
<th>Indicator</th>
<th>Achieved/or not?</th>
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| HSRC will provide overall leadership and technical assistance on the project as well as project management. | Achieved  
The HSRC has co-led processes of survey implementation in all 9 provinces through its staff being engaged as provincial coordinators due to their experience in survey work. The HSRC staff has been working under the two project managers drawn from the PLHIV sector. |
| Both SANAC and Wits Reproductive Health Institute (WRHI) as co-funders of the project will both participate in the Stigma Index Committee and also manage their separate grants for the study. | Partly achieved  
Only SANAC has been participating in the Committee. As indicated above, WRHI has not participated in the Committee as required. |
| In addition, WRHI will also provide some technical assistance on the project together with the HSRC. | Not achieved  
WRHI has not provided some technical assistance on the project together with the HSRC |
c. The Stigma Index Committee

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<tr>
<th>Indicator</th>
<th>Achieved/or not?</th>
</tr>
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<tbody>
<tr>
<td>The Stigma Index Committee comprises of organisations of the PLHIV sector, research programmes, and development partners.</td>
<td>Achieved</td>
</tr>
<tr>
<td>• The HSRC coordinates the implementation of the Stigma Index Committee Meeting, by preparing the minutes, and agenda for each meeting</td>
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<tr>
<td>• The Stigma Index Committee(^2) has a conference call, with representatives of SANAC, UNAIDS, TAC, NAPWA, PWN, GIZ (who provided some of the SANAC funding) and so forth every two weeks. University of Pretoria Centre for the Study of AIDS have also been represented from the start.</td>
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<tr>
<td>• Weekly project management (two project managers, data capturers, provincial study coordinators) meetings have been scheduled; PLHIV sector has also been invited to our weekly project meetings (starting from the middle of October) in order to elicit advice on some of our fieldwork challenges and also to keep the sector informed of all data collection activities. This also serves as part of capacity building for the sector as required.</td>
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</table>

\(^2\) Attempts to involve WRHI have failed.
Study design and implementation

Who took part in the Stigma Index Study?

The study involved PLHIV aged 15 years and older. All persons were linked to an organisation for PLHIV or attending health facilities and NGOs for the purposes of accessing support or care related to HIV and AIDS from 18 districts. These districts include 9 pilot districts of the National Health Insurance (NHI) and other 9 districts that are non-NHI pilot districts from each province. Thus, the study population is PLHIV who can be identified from these districts. The districts have been identified on the bases of accessibility due to the link with the NHI pilot program being implemented in these districts and the need to have both urban and rural districts included in the study. This means, if the NHI district is mostly urban then a generally rural district in the same province was sampled. Hence the results are versatile in informing the futures phases of the program and other activities in other districts related to stigma among PLHIV.

The study is taking place in the following nine pilot districts of the NHI programme and an alternative district in each province as shown in Figure 1. The districts include the following:

1. Eastern Cape (OR Tambo and Buffalo City)
2. Mpumalanga (Gert Sibande and Ehlanzeni)
3. Limpopo (Vhembe and Waterberg)
4. Northern Cape (Pixley ka Seme and John Taolo Gaetsewe)
5. Kwa-Zulu Natal (uMgungundlovu and Umkhanyakude)
6. Western Cape (Eden and Cape Town)
7. North West (Dr K Kaunda and Ngaka Modiri Molema)
8. Free State (Thabo Mofutsanyane and Mangaung)
9. Gauteng (Tshwane and Sedibeng)

The list of PLHIV does not exist and thus institutions that provide support to PLHIV in these districts were used as the sampling frame. In the sampled institutions, individuals living with HIV and accessing services were invited to participate in the study. PLHIV were primarily recruited from existing support group structures that are coordinated and managed by the SANAC PLHIV Sector (i.e. TAC, NAPWA and PWN).

The study is targeting about 10 800 respondents from 18 districts. To date, over 7 000 PLHIV have been interviewed. Thus far, two thirds of PLHIV who were recruited into our study are women with one third consisting of male survey participants. Concerning the age distribution of participants, most who took part in the Stigma Index Study are from the 25-29 and 30-39 years old age categories. Most survey participants reported to have been living with HIV for the last 2 to 9 years. There is a mix of responses with regards to current relationship status, with survey participants, reporting to be “in a relationship, but not living together”, whilst others reported being “married or cohabiting with either husband/wife/partner”. There is a substantial proportion of PLHIV who have also engaged in same sex relationships in their lifetimes. Hence the survey also reached those “hidden and “hard – to - reach” key populations. Thus experiences can be extrapolated to only focus on key populations (i.e. MSM, lesbian and gay individuals, prisoners, 

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3 Of 3999 questionnaires that have been captured thus far.
injecting drug users, migrant workers, sex workers and refugee and so forth) if need be. Often, men who identify as “gay” or “bisexual”, experience the stigmatisation of engaging in same sex behaviours and that of a HIV positive status (i.e. double stigmatisation). With regards to employment, survey respondents, reported that they were in the following employment sector: Government; private for profit sector, private not for profit, agriculture (i.e., farming, food processing), industrial, service and finally the informal sector. Finally, the cost of living is a concern for many families living in South Africa. Data revealed that survey respondents, reported “not having enough money for basic things like food and clothes” as well as some who had “money for food and clothes, but fell short on many other things”.

Figure 1: Distribution of sampled districts
What do we know thus far of the stigma and discrimination experienced by PLHIV in South Africa?

Real experiences of stigma and discrimination

We assessed stigma and discrimination of PLHIV, as being socially excluded (i.e. family gatherings, religious gatherings, workplace activities), being verbally and physically assaulted because of ones HIV positive status and being denied access to work, health and education services as well as being gossiped about. These experiences of stigma and discrimination were recalled in a 12 month period. Data revealed that a substantial proportion of survey respondents have been aware of being gossiped about regarding their HIV positive status at least, “once” and “a few times” in the last 12 months. This is evident in the following quotations:

“I was gossiped about and I knew the people who gossiped about me because of my HIV positive status”

“My neighbour saw me at the clinic and she gossiped about me”

“People gossip about my status they said I’m going to die”

“My husband was sick, neighbours talked about it, that his ex died of being HIV positive and that my children are also positive”

“People were gossipping and discriminating against me when I was looking very sick”

As a consequence of this, some of the survey respondents reported being excluded from social gatherings or activities (i.e. weddings, funerals, parties and clubs) at least “once” and having been excluded from religious activities or places of worship in the last 12 months because of their HIV positive status. Moreover there is also evidence of exclusion from workplace activities:

“Although I disclosed to my boss, I saw that she misjudged me about my status and my age”

“I was once sick and my weight loss caused a lot of questions at my workplace”

“I was discriminated of my HIV status at work”

The Stigma Index Study found that some PLHIV have experienced stigmatisation and discrimination in the communities in which they live:

“A community member heard that I am HIV positive and told others that I might infect other people in my community”

“After I disclosed my HIV status to the people around my community, then they started to discriminate and stigmatise against me”

“I disclosed then the community treated me differently and they changed their attitude towards me”

“I was diagnosed and tested HIV positive so I was discriminated upon by community members”

“At our local clinic they are very caring because when we are collecting medication we can be seen by anyone that we are collecting medication that is when people discriminate upon us as people living with HIV”
Verbal insults, harassment and threats because of HIV positive status, were also mentioned by some survey participants that occurred at least “once” during the last 12 months. There was also evidence of physical harassment and threats that occurred in the last 12 months at least “once” or “a few times” because of their HIV positive status. Survey respondents revealed that individuals who physically assaulted them because of their HIV positive status included the following: “My husband/wife/partner”, another member of the household” and a “person outside the household who is known to me”.

“My husband does not want to touch me sometimes and he does not want to eat my food. He also called me names, like you are a bitch and so on”

“My child died from being HIV and I was insulted by the family of my boyfriend”

In addition to being verbally insulted by intimate partners, people still experience stigma in the safety of their family homes, with survey respondents indicating that they have at least “once” and “a few times” experienced exclusion from family activities in the last 12 months:

“At home they could not sleep or touch my food because of my condition”

“At home they were not happy about HIV status so they kept my things away from their such as a blanket and so forth”

“One of my family members did not want to eat the food that I have prepared”

“I was excluded from other family activities not shown love like other children”

**Feelings of self-stigma**

There is evidence of internalised stigma (self-stigma) among survey participants. With some survey participants having expressed feelings of shame, guilt, self-blame, low self-esteem and feeling suicidal.

“They are not HIV positive they always make me feel dirty and useless”

“I feel dirty and I didn’t understand how I got the virus I had so much hate for everyone. I blamed all the females that I knew I was scared and frustrated. I felt lonely and suicidal”

“I felt so bad about my status feeling of shame”

As a result of this, feelings of self-stigma led to others developing a substance use problem, and because of this were often excluded from family gatherings:

“I was excluded because I am an alcohol abuser”

“After knowing my status, I started drinking alcohol and abusing drugs. When I am high I use to insult people with bad things”

Moreover because of internalised stigma, survey respondents indicated that they have chosen not to attend social gatherings, and have isolated themselves from family and friends. Of concern is that some reported having avoided hospital and the local clinic because of feelings of self-stigma.

Feelings of self-stigma were worsened when PLHIV were symptomatic. This also increased stigmatisation and discrimination against them in the communities in which they lived and their places of work:
“I was stigmatised because I fell sick, and people suspected that I was HIV positive because of the symptoms that I had when I was sick”

“Because I lost weight, people were thinking that I am sick, so they were saying lots of things about my skinny body”

“I lost weight and I got sick for a very long time”

“I was losing weight people started gossiping about me”

“I was once sick and my weight loss caused a lot of questions at my workplace”

**Rights, laws and policies and effecting change**

We asked survey respondents, whether they have heard of the Declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV? If they have ever read or discussed the content of this Declaration?

Although we found a substantial proportion of PLHIV who responded that they were aware of the protection of their rights, the everyday application of those rights were often denied. For example, some were denied health insurance or life insurance because of their HIV positive status; others were forced to submit a medical or health procedure. There was also evidence of survey respondents being aware of the following organisations or groups that can provide support to them when they experience stigma or discrimination: PLHIV support groups; networks of PLHIV; local NGOs/CBOs; faith-based organisations (FBOs); a legal practice; a human rights organisation; a national NGO, and an AIDS Helpline.

Survey respondents mentioned that they had sought the assistance of the above-mentioned organisations, with some indicating that the following stigma and discrimination events happened to them:

“A family member verbally discriminated against me at a family gathering about my HIV positive status, I was told not to touch the food nor help with the cooking”

“About my HIV status, my family members do not want to eat together with me”

“After my ex-husband’s death, my in-laws kicked me out of their house and took my kids away, accusing me of killing their son”

Some have found support for stigma and discrimination that they experienced within their support groups and with their local NGOs/CBOs, networks of PLHIV organisation (e.g., TAC, NAPWA), and the AIDS Helpline:

“About people gossiping and don’t know what to do but the support group helped me and groomed me”

“After that harassment story I met with my local NGO they encouraged me to talk with her to stop what she is doing”

“I asked for help for someone they were discriminating and my friends as well, so I consulted, TAC, NAPWA and support group to resolve the matter”

“I was suicidal so I called the AIDS Helpline”
Survey respondents indicated that they have supported other PLHIV in terms of emotional and physical support as well as referral to other services. Although survey respondents provided emotional and physical support to other PLHIV, there was still a need for organisations which advocate for the rights of PLHIV; for organisations that provide emotional and psychological support, and in particular for organisations that advocates for the rights of key populations such as MSM, injecting drug users and sex workers.

**Testing/diagnosis**

We asked survey participants as to their reasons for testing for HIV. There was a mix of responses, including the following. Although the dominant response was because survey participants fell sick or lost weight:

“Because I was sick before, then I decided to check and know my status”

“I was feeling sick every now and then”

“I was sick with a headache and had tonsils”

“I felt weak and I was losing weight also I had a cough for more than two weeks and the doctors advised me to test”

“I lost weight and they said I am having high blood pressure and the medication did not work and they when they tested me”

“I was continuously ill because I couldn’t eat, sleep and I felt numb, dizziness, my ankles and knees were very painful”

Some were diagnosed with TB first and then tested for HIV:

“I was diagnosed with TB and STI symptoms”

“Because of TB diagnosis”

“I had TB symptoms”

Others were tested because they wanted children:

“I am saying pregnancy because my girlfriend was tested HIV positive when she was pregnant”

“I wanted a child”

“Because I want my baby born healthy”

Most survey respondents tested for HIV in a public health care facility, and did so out of their own accord.
Disclosure and confidentiality

We asked survey respondents regarding their experiences of disclosure of their HIV positive status, and whether or not their status was disclosed by others or they informed those individuals themselves. The majority of individuals disclosed their HIV positive status themselves to their intimate partners, other adult family members, children in the family, friends and neighbors, colleagues and so forth. Reports of feeling pressured to disclose to other individuals not living with HIV though were also evident. Some of the reasons listed by individuals included the following:

“When I came back to the clinic one day my boyfriend told me to tell his mother about my HIV status, because he cannot do that”

“Family member had a concern about my child hearing about my HIV status from other people so she advised me to disclose to the child”

“While I was pregnant one day my friend asked me if I went to the test and even ask me what were the results and I was not ready to tell anyone by that time”

Treatment

We asked survey respondents if they are currently on ARV treatment and whether they have access to treatment. The overwhelming majority of our survey respondents indicated that they are currently on ARV treatment and that they have adequate access to treatment. This is an important indicator of the success of the ARV roll out plan. In addition we also assessed whether survey respondents have had constructive discussions with a health care professional and a trained peer educator on HIV related treatment options as well as constructive discussions on subjects such as sexual and reproductive health, sexual relationships, emotional wellbeing and so forth. Although the overwhelming majority of survey participants indicated that they have access to treatment, fewer responded to having had constructive discussions with a health care provider or a trained peer educator on HIV related treatment options as well as on sexual and reproductive health, sexual relationships and issues of emotional wellbeing.

Having children

In this section we examined whether the reproductive rights of PLHIV were protected, in terms of having received counselling about their reproductive options; being advised to not have children because of HIV positive diagnosis; being coerced into sterilization because of HIV positive diagnosis; being advised to terminate pregnancy and so forth.

TB – related stigma

Our survey found that having HIV and having been infected with TB contributes to experiences of stigmatisation. This is evident in the following quotations:

“I was discriminated because of my HIV status and having TB”

“I educate one of my friend, family because they were discriminated my friend because he had TB and HIV”

“People were gossiping about my TB status”

“I felt stigmatised because of my HIV and TB status”
A survey conducted by and for people living with HIV

Ensuring that the process of implementing the Stigma Index Study is an empowering one for PLHIV is an important aspect of the survey. The implementation of the study goes beyond the overall research purpose. We asked interviewers, supervisors, and data capturers to share their experiences of being involved in the implementation of the study. Below are some of the experiences of our fieldwork teams.

**Interviewers**

**What were some of the experiences of face to face interviewing?**

“At the first time face to face interviewing was seen to be challenging because it was the first time [I was] interviewing people. So some people use to say lots of things during the interview. So that makes [it difficult] to give a full listening. Sometime questioning used to bring back memories so in those situations you as an interviewer you have to give him time so that is experience to understand that the person experienced lots of challenges so while giving answers you need to give him time not to rush him” (Interviewer 1: uMgungundlovu District, KwaZulu-Natal)

“Men are not willing participants. If one is known they are not opening up. I feel that interviewees are in need of psychosocial support. They are willing to work in support of the government’s interventions” (Interviewer 1: Gert Sibande, Mpumalanga)

“The most important experience working in this study was to learn some of the experiences of the participants. The way that most engaged was not expected. I think it also made me to be passionate about this work, to wake up every morning to speak to people about their experiences. Most of the participants were not difficult to work with. I learnt to be more passionate, to be understanding and to love” (Interviewer 1: Mangaung, Free State)

“Some people seemed to be afraid of us. Others talk about their experiences of more than two years. Others don’t want to be honest” (Interviewer 2: Mangaung, Free State)

“Some people are very shy when they have to answer questions on face to face due to cultural background. So others they feel that you undermine/disrespect them especially the elders” (Interviewer 3: Mangaung, Free State)

“Some individuals were not cooperating at all some were using politics, but any ways I learnt a lot from other people” (Interviewer 4: Mangaung, Free State)

“By giving them enough time to speak they become more relaxed and sharing stories helped them to see that they are not alone” (Interviewer 3: uMgungundlovu District, KwaZulu-Natal)

**Have you gained any skills and knowledge as an interviewer in the Stigma Index Study?**

“Yes I did gain new skills and knowledge because as an interviewer you need to listen to an interviewee and take every word he/she says whether you like it or not, you need to pay attention but first you need to know everything in the questionnaire because there are times where you need to clarify questions to an interviewee so if you don’t know your story people do not listen to you because they think you don’t know what you doing, and again Stigma Index has confidentiality so if you cannot keep a secret you may end up disclosing people’s status which is not good although I knew that it is not my place to talk
about other people’s HIV status but this study has made it clear” (Interviewer 1: uMgungundlovu District, Kwazulu-Natal)

“I experience that I need to listen attentively to the interviewee, and to put yourself on that particular person’s shoes to feel what she feels I also experience to put myself in the level of my clients, and also to be strong when the interviewee becomes emotional” (Interviewer 2: uMgungundlovu District, Kwazulu-Natal)

“The new skills and knowledge as an interviewer that I joined from this stigma index study, is that I need to listen to my client attentively, put myself on his/her level, empathy” (Interviewer 2: uMgungundlovu District, KwaZulu-Natal)

Supervisors

What skills and knowledge, if any have you acquired since you have started working here at the HSRC in your current position as supervisor?

“Firstly I have learned more problems solving skills. Taking decisions when necessary in a short time. Managing different people from different organisations with different backgrounds and attitude. Listening without interrupting and judging. Work under pressure to meet deadlines. I have also learned how to encourage the group and individual to perform the duties at best. I have also learned communication skill. I have also learned planning and reporting. How to manage and account for finances” (Supervisor: uMgungundlovu District, KwaZulu-Natal)

“I haven’t really acquired any skills from this position as I came here being a leader from my organisation, I only was required to do adjustment as I am working with a team that didn’t know the importance of team work at the beginning yet they have improved as of now” (Supervisor: Tshwane District, Gauteng)

When you return to your organisation (TAC, NAPWA) would you be able to use some of these skills? (Please provide explanation, as to why or why not, and which skills that you have acquired will be used) to enhance your organisational structure?

“Yes my organisation is TAC and I will use some of these skills I have acquired such as listening skills when we having meetings. Also communication skills to during meetings. Last but not least I will use problem solving skill when we have problem to solve. I also believe panning and reporting will come very handy” (Supervisor: uMgungundlovu District, KwaZulu-Natal)

Have you been able to use some of your advocacy and activist skills effectively in your position as supervisor? Please explain (yes or no?)

“Yes there was this young adult lady in a place called Howick (Mevana ) area who was not serious about adhering to her TB medication as a result I felt she was putting her sons life in danger of getting infected with a drug resisting TB. So I advocated for her son and spoke to the Doris Goodwin TB facility to take her in and his son was left at home with her grandmother” (Supervisor: uMgungundlovu District, KwaZulu-Natal)

“Absolutely yes. My job responsibilities included managing logistics and also administration. The skills gained will be beneficial to the organisation” (Supervisor: Mangaung District, Free State)
Data capturers

What skills and knowledge if any have you acquired since you have started working here at the HSRC in your current position as data capturer?

“We have acquired skills more on data capturing and especially some of the new things on Excel and knowledge of how to do quality checks and communication skills” (Data capturer 1)

“I have acquired more communication skills and mostly the teamwork or teambuilding. And also I have acquired the skills of managing pressure. First it was my first time working in my entire life so HSRC has introduced me to the field of work. Also my typing speed has accumulated. I have gained more skills on Excel” (Data capturer 3)

“I have gained a lot of knowledge especially working under pressure towards that week of the payment cut off dates, and I am very thankful to HSRC for granting me the opportunity to work as their data capturer it will make a positive effect on my CV” (Data capturer 4)

Please share some of your experiences in your role as a data capturer that contributed to the progress of the study and if this had made an impact on increasing your self-confidence?

“We had to work under pressure, and work over times, work even on weekends. Yes it has made an impact because I didn’t know there are some of the things that I can do on my own without being under supervision” (Data capturer 1)

When you return to your organisation (TAC, NAPWA) would you be able to use some of the skills and knowledge that you have gained? (Please provide an explanation, as to why or why not, and which skills that you have acquired will be used) to enhance your organisational structure?

“Yes I will be able, first and foremost TAC is the organisation for people so it is very important for people to work together, cooperate towards the same goal. That will be in manifest through the teamwork that I have acquired from the HSRC. And for the team to be strong enough it needs strong and proper communications to be alert” (Data capturer 5)

“The experiences in my role that has contributed to the progress of the study is when doing quality checks. This bring [to] my attention that living with HIV is not a death sentence as you can live your life to [the] fullest and achieve your goals as well as being confident about talking about your status by choice. I was afraid to talk about my status but working on this study brought a lot of confidence into myself and I would like to thank my organisation TAC and HSRC for bringing the best in me” (Data capturer 5)
Conclusions

Although the study is nearly completed some interesting qualitative data has started to emerge which was presented in this report. The data suggests the presence of internalised HIV-related stigma and discrimination among PLHIV interviewed which range from the home to the community and is also seen in health facilities. It is interesting to note the important role that some support groups and with their local NGOs/CBOs, networks of PLHIV organisation (e.g., TAC, NAPWA), and the AIDS Helpline play in mitigating stigma and discrimination.
References


