

Disparities in attitudes towards People Living with HIV/AIDS (PLWA): A Nationwide Study

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Abstract:

A nationwide study on the association of HIV/AIDS with stigma has implications for the way in which individuals, families and communities relate to people living with HIV/AIDS, and also to children who have lost their parents. Sub Saharan African is estimated to have 29.4million HIV positive people, while 10 million young people (age 15-24) and almost 3 million children, under the age of 15, are considered to be living with HIV/AIDS (UNAIDS/WHO, 2002). In addition to human suffering, discrimination against the infected may lead to rejection and social isolation. The aim of the study was to examine the social and cultural context of HIV transmission and prevention within the various racial, ethnic communities in South Africa. It is part of South Africa's First Population-based HIV/AIDS behavioural risks, saliva and mass media survey, conducted in 2001 –2002. Qualitative methods were applied, 29 key informants and 39 focussed group interviews were conducted in 9 provinces in South Africa. Key informants included religious leaders, traditional healers, traditional leaders and youth initiation leaders. Focussed group discussions included male and female participants from a variety of ethnical and racial backgrounds, age groups and geographic locations. Interviews in the urban areas were conducted with mixed groups, lesbians Jewish and coloured male and female groups. All transcripts were coded employing both deductive and inductive methods using Atlas.Ti and PEN-3 model for data analysis, respectively. The study found that in respect to social context, age gender and religious background still greatly influence social attitude towards PLWA. Peoples beliefs systems tend to inform the way in which HIV/AIDS is understood and interpreted.

Aim:

To understand the attitudes and behaviours to people's responses toward PLWA and to identify entry points by which interventions can be implemented.

Specific objectives:

- To understand the social and cultural context of PLWA
- To understand the degree of stigmatisation
- To help in the development of programs and policy interventions aimed at seeking to improve the lives of PLWA and affected families.

Methodology:

1. Development of focus group guides and key informant interview schedule

HSRC and its research partners, CADRE and MRC, collaborated in developing Focus Group (FG) guides and Key Informant (KI) interviews designed to gain an understanding of the meanings people attribute to HIV/AIDS prevention, care, and support. A "Focus group interviewing" instrument from the HSRC was adopted as a guide for the development of the interview schedules

2. Representation of Cultural groups

All the main cultural and sub-cultural groups in South Africa were represented in the focus groups. Apart from reflecting the rich cultural diversity of South Africa, it was also essential that there be a balance in terms of gender (male versus female) and age (youths aged 18-24 years of age versus adults aged 25-49 years of age) where possible.

3. Selection of focus group participants

To confirm information on community knowledge, beliefs, perceptions, and behaviours that may already be available but not clear, focus group discussions were conducted in 9 provinces, in rural and urban areas. The selection of participants was preceded by training and selection of facilitators and regional coordinators who could communicate in the various regional languages including English and/or Afrikaans. Group discussion facilitators included researchers from NGOs, universities, HSRC, MRC, and CADRE. FG participants were selected on the basis that they would provide insights into the meaning of the behaviours and practices within the identified research area as perceived by the various cultural, social, and age groups found in South Africa. The strategy was to promote the participant's self disclosure through the creation of a permissive environment by exploring in greater depth socio-cultural practices in

HIV/AIDS context. Participants were selected according to their respective gender groups, taking into consideration their age, language, religion, and racial categories. For example, there were youth (18-24), adults (25-49), and mature adults (49 plus). To allow for variety in the urban settings there were mixed youth groups, gay, lesbians, Muslim adult, Jewish adult, and Coloured male and female groups.

4. Selection of Key Informants

Detailed information was gathered from mature adults who were considered knowledgeable about the HIV/AIDS topic and had cultural experience about local beliefs and practices in the respective communities. The Key informants included Chiefs, Traditional Healers (male and female) and Religious leaders (Apostolic Faith, Protestants, Catholic, Jewish, Islam, African Independent church, and Hindu Priests).

5. Training focus groups

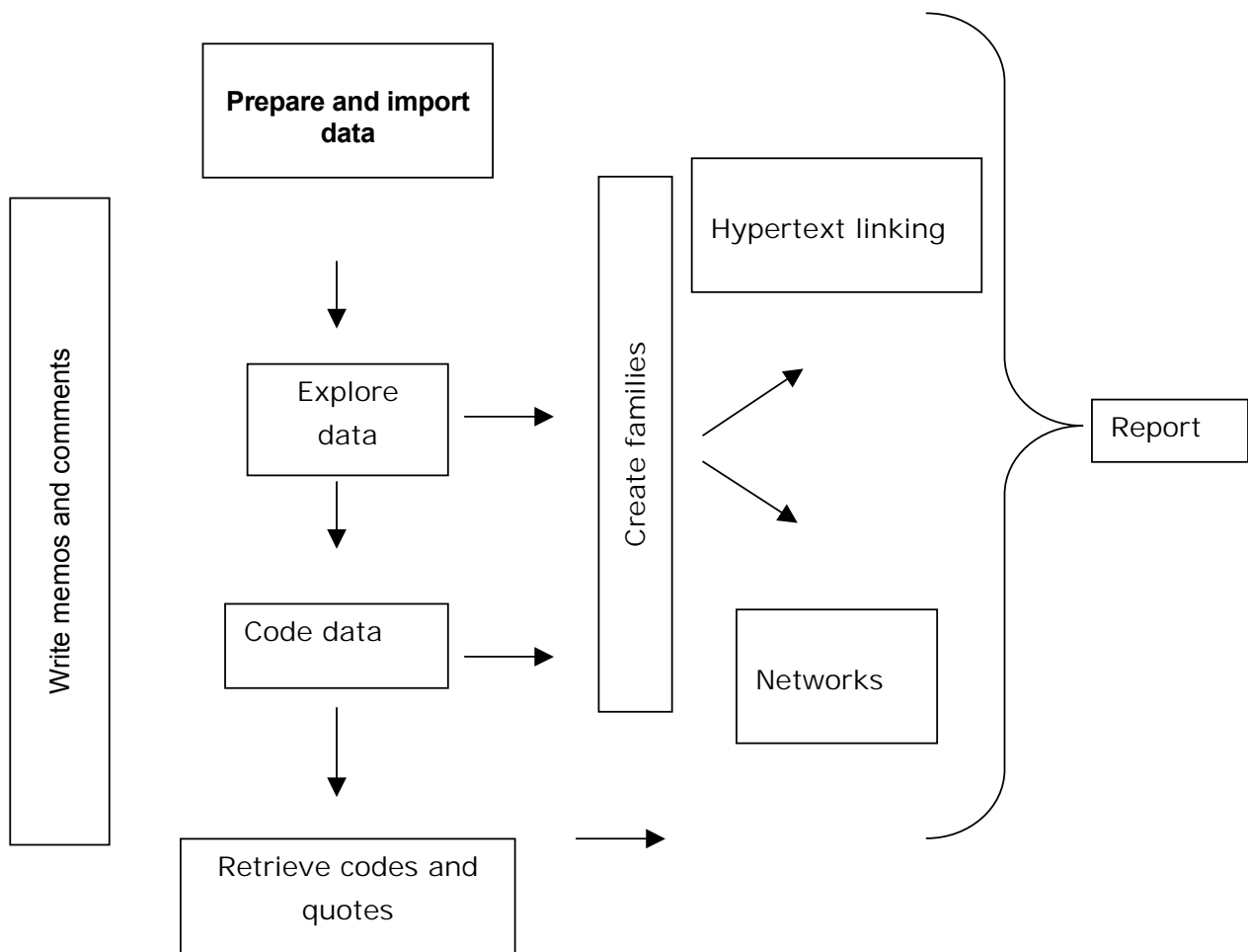
A 3-day training workshop was organized at the HSRC Conference Centre in Pretoria for all 37 focus group facilitators/key informant interview drawn from all the nine provinces in the country. The training involved the following aspects:

- Introduction to the SABSSM project.
- Finalisation of work plan and determination of the number and composition of focus groups.
- Finalisation of focus group guide/questioning route and other issues.
- Broaching sensitive issues, e.g., sexuality. This issue is discussed a bit more below in view of its significance for as well as its centrality to this study.
- The role of ethics and informed consent in research. This was linked to the importance of appropriate community entry for research in the South African context.
- How to run a focus group.
- Role playing running a focus group first in English and later in another local language.
- How to conduct a key informant interview.
- Role playing running a key informant interview first in English and later in another local language.
- How to use the audiotape recorders during interviews.
- How to use the transcribers machines and prepare transcripts of the focus group discussions or key informant interviews.
- The time plan for the project.
- The logistics of conducting the various focus groups and key informant interviews including selection of participants, selection of venues for running either focus groups or interviews and provision of refreshments to participants.
- Clearly understanding the respective roles of regional and provincial coordinators as well as the focus group facilitators/key informant interviewers.

Training on ATLAS.ti

- Computer Assisted Qualitative Data Analysis Software (CAQDAS) course offered to HSRC staff and interns
- A two-day course on Atlas.ti was given to an HSRC team and to a group of interns. Atlas.ti was used to begin a process of coding and analysis of focus groups carried out in a national project examining cultural attitudes towards sexuality and HIV Aids.

GENERAL WORKING PROCEDURE OF ATLAS.ti



Data Analysis

After all of transcripts were coded and the codes were assigned to their appropriate thematic area, the data was analysed and organized to capture its multiple and diverse

levels. The data was analysed by the 15 thematic areas and organized to reflect the data available by province, ethnic/racial group, age group, geographic location or key informant.

The four final major themes and sub-themes were:

1. Gender inequity
2. Stigma, denial, and discrimination
3. Economic inequity
4. Belief systems and interpretation of health and illness – HIV/AIDS

8. Results

In South Africa, stigma continues to be a major barrier to effective HIV/AIDS prevention and treatment. In this country there is still a belief among some groups that HIV is a problem of another group. People or groups are set apart from the group that defines itself as normative through “othering” and labelling on the basis of any number of characteristics including physical attributes, socio-economic status, sexual preferences and practices, religious beliefs, race, ethnicity, and association with disease, amongst others.

The study showed that stigma is “felt” or perceived among the PLWHA at the individual or group level. Perceived or felt stigma perpetuates denial, influence risk reduction behaviour, inhibit HIV testing, involve avoidance of disclosure, or limit treatment seeking by a PLWHA. I

Perceptions Positive

The notion of support with the aim of providing hope is evident in the response below:

“I think if some(one) has AIDS I can treat him/her well. I can give him/her some advice and try to console him/her that it does not mean that it his/her life is over. I will spend most of the time with him/her and I can even eat with him. I will also trust him.”

(Youth_rural NP, Pedi)

In a similar vein, there was an understanding that stress and anxiety were problematic for PLWHAs.

“And what mostly kills these people is anxiety and depression, so we need to support them” (Female, rural Eastern Cape, Xhosa) and “Most of people do not die because of HIV/AIDS. But a lot of them die from heart attack when they learn that they are HIV positive - your life is deteriorating from that point”

(Youth, rural Mpumalanga).

Perceptions Existential

Interviewer: If you are with them in the community how do you feel about them? Do you not feel like discriminating against them?

“ It does not happen because I work with them most of the time, when I am with them I try by all means to be strong and not show them that I am aware that this disease is going to kill them. I make them realize that AIDS is just like any other disease like a headache or a stomach ache, that can kill, like being killed in a car accident even when you do not have HIV you can be shot (so they cannot run away from death). We keep them strong by saying that they should not isolate themselves. They should go out and be with people. They should take care of themselves; they should not have sex without a condom by thinking that since they are already infected, the person should continue protecting themselves by wearing condoms. They should do exercises and accept that they are sick and not pretend as if they are not sick and talk about ‘idliso’ or ‘witchcraft’ and that if they tell themselves that they are HIV positive they will protect themselves and live a longer life.”

(Female Virginity Tester KZN)

San respondents, in contrast – referred to HIV/AIDS as the “Great Disease” providing some distance from the notion of AIDS as something that requires explanation in all its facets –

“We cannot remove the person who has the Great Disease from us. We have to keep him with us, so that we have to make him healthy

(Female, San, Northern Cape).”

Perceptions Negative

“We learned that it was founded from the American soldiers who were in exile. They spent a long time away from their families. As a result, they had sexual relationship with monkeys. Hence it is called HIV because the monkey and human beings are closely related. They had sexual relationship with the monkeys.”

(Youth, rural Mpumalanga, Ndebele)

“AIDS is caused by having sex. In the past we did not have it in our community. It has been brought by foreigners and use the way I said earlier that he hires a room here he will infect all the women here. I say it came with foreigner because in Sotho we have all disease names but this one we do not have it”.

(Traditional leader, NP Sotho)

"I can also say that where I come from you know I've been to Qumra there is a mixture of Coloureds and Xhosas. So what is sad there is that there is a high rate of AIDS. There are also those people who can't speak Xhosa who are called kwerekweres who come from these countries they also go to Qumra . What is happening is that we tend to sleep with these people without using a condom so that's how we catch this disease. So that's why there is a high rate of HIV/AIDS in Qumra."

[Male youth Rural Eastern Cape Xhosa]

But I think that the perspective of a lot of people. Actually, think a lot of people... see it as a Black disease. They don't see it as a White disease. Uhm... And... I know...we did a kind of project for a media course. And we spoke to a British student, and she said to me, "Well, I'm white. Why you're speaking to me? /Uhr/... The Blacks...!" She just said it's Black disease. It doesn't happen in /other cultures/... And... Ja! Because like we showed her these adverts. And we said, do you they're good? Whatever... And she said, "Well! The Black people can't understand them. And this is a Black disease!" /ja/ So, people believe that. I mean this is... first year UCT [University of Cape Town] student. She believes that! So you can't... I mean that becomes a problem when it's...when you doing culture specific things, people see it as a Black disease.

(WC-Adult Female Urban Jewish).

Understanding of felt stigma reflected disempowering aspects of HIV infection. For example:

"It is these kind of attitudes and beliefs, which make HIV positive, people to distance themselves from the community because they are rejected even before we reject them"

[Youth, rural Mpumalanga].

Enablers Positive

There was a strong sense that interaction with PLWHAs was critical to both understanding and the erosion of stigma.

"They did that talk at school one day when they brought actual people with AIDS, that I've never forgotten and I think that listening you get glued in as you sit there. It hits fear and it hits a lot of things."

[Female Urban Eastern Cape, mixed].

Others in the same group offered supporting perspectives:

“Because that day you actually watching this person being handled onto the podium thing and she walked down from the stage in between the rows where you are sitting and you just want to curl up and die yourself. You get to really listen and I found that there were a lot of other talks that we’ve had where I’ve heard things for the first time.”

[Female Urban Eastern Cape, mixed]

“You could let those people talk on TV but that’s already distancing them, the only reason that it works is because it’s in your face and its close.”

[Female Urban Eastern Cape mixed]

“But knowing from the community that we come from that you’ll get a lot of people that will be nasty towards this person that’s got AIDS because knowing the way some of them speak they can be very nasty to this person by saying things or talking in a way that he, he or she will be able like you know for it to fall into their ears it will be hurtful to that person”

[Female urban KZN Muslim].

Enablers Existential

Strong sense that AIDS could be addressed at the level of local care resources. There was little distinction between the values There was a of “Western” (biomedical) and traditional health care systems. Respondents suggested encouraging a person to go for treatment “... either to doctors or traditional healers”, “I can advise the person to try several options for survival”.

Enablers Negative

“Drunk people are quick to get horny and sleep around. They are unable to control themselves when they are under the influence”.

[Female Rural Free State mosotho]

“Ja the general thing is that the minute that you come out and tell people that you’ve got AIDS, it’s always like “That’s what you get from sleeping around” so you can never get sympathy if you’re suffering from AIDS.”

(Female Urban Eastern Cape mixed)

“Vat-en-sit is everywhere, particularly in areas like Dark city and Mandela Village sections. In Vat-en-sit women throw themselves

on working men by moving in with them. Eventually they stay together in a shack house”.

Nurturers Positive

The spirit of ubuntu, caring and non-discrimination forms an important cornerstone for building a positive framework for response. In the example below, this is led by pragmatic guidance offered by a father to his daughter. Non-discrimination is also incorporated into a preventive message.

“My dad always says (we run a hostel at home) that we must treat everyone as if they have AIDS as well as yourself, that’s the only way that you can be safe because you actually can’t tell.”

(Female Urban Eastern Cape mixed)

This is further echoed within the context of compassion and dignity.

“The emphasis should be on the awareness, and on the support for people who are HIV- positive. They say it is a disease, and there should be compassion you know...for these people, the dignities of these people, that should be where the emphasis lies.”

(Religious leader Gauteng Catholic)

“I think its through having trainers, facilitators who have this knowledge to go into communities and lecturing, I mean people from NAPWA for example who are HIV are trainers of home based care, given all sorts of things from the people who have experience themselves that becomes credible, viable, that becomes real, not somebody who is on the outside who just has little knowledge, to use the people who are sufferers”.

(Religious leader Eastern Cape Protestant)

Nurturers Existential

The principle of non-discrimination was well articulated by a number of respondents. This is grounded in an understanding of the need not to attribute blame, nor to fear infection.

“Oh! those are my friends. I have no problem, I work with them, stay with them. It’s just that sometimes you need to reassure them especially when it comes to counselling. Reasons for my actions to them is that some of them did not take HIV virus into their bodies by themselves, it came through different ways and another thing is that this person is not your enemy only because they are HIV positive. They are not going to infect you with HIV. They are just like anybody, a person with Cancer cannot pass it to you, it’s just that they need to be loved.”

(Male initiation leader Eastern Cape Xhosa)

This type of acceptance is further evidenced in the quotation below where a respondent talks about his HIV positive brother, but runs alongside caution by the brother himself.

“I meant that his life span was shorter than mine due to the virus. I remember one day when we hand-greeted him. I waited for my turn and it did come, I gave him a firm hug until he say let go. I used to share a bed with him. At times I realised that the fact that we were sharing the same bed made him to isolate himself. Probably because he thought of himself as being contaminated by an HIV virus. Therefore I presume he thought it was safer for me if he keeps the distance.”

(Youth rural Mpumalanga mixed).

Nurturers Negative

“Personally I do not fear death. You know this disease. I do not want to be defeated by something, but I can feel that this thing is a strong killing machine, and it’s fast. They call it M3 [BMW]. That thing kills. It is running, I am telling you.”

(Male rural Mpumalanga Ndebele)

Fear is also more generally expressed in association with PLWHA, but may also underpin the individual’s motivation for prevention.

“... there’s a world of people being scared of being with people with AIDS, I was one of them, I was very frightened, because until I went for that previous eh you know this thing to know about AIDS, I was, Would never even come to... meet face to face with a person with AIDS, I’m frightened to even touch the person’s hand.”

(Female Urban KZN Hindu)

Conclusion:

The study highlights the differences in attitudes amongst the participants and the groups and this calls for implementation of appropriate policies that are locally relevant for PLWA.

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