FEAR OF STIGMATIZATION AS BARRIER TO VOLUNTARY HIV COUNSELLING AND TESTING IN SOUTH AFRICA

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Abstract

Objective: The objective of this qualitative study was to identify psychosocial correlates of HIV voluntary counselling and testing (VCT), with an emphasis on the association between fear of AIDS-related stigma and willingness to have an HIV test.

Methods: The study was executed in Limpopo Province at University of Limpopo, Polokwane, South Africa. Focus group interviews were held among 72 students, divided over 10 groups.

Results: Results showed that participants had different levels of knowledge about HIV/AIDS and VCT, and that AIDS was still strongly associated with ‘death’. Results further demonstrate that HIV/AIDS related stigma is still a very serious problem in South Africa. Lack of HIV/AIDS related knowledge, blaming persons with HIV/AIDS for their infection, and the life-threatening character of the disease were seen as the most important determinants of AIDS-related stigma. The main benefit to go for VCT was ‘knowing your HIV status’, whereas main barriers for testing were ‘fear of being stigmatised’ and ‘fear of knowing your HIV positive status’.

Conclusion: Fear of stigmatization is an important barrier to HIV testing and has negative consequences for AIDS prevention and treatment. Interventions to reduce HIV-related stigma are needed in order to foster voluntary HIV counselling and testing in South Africa.

Introduction

For nearly two decades countries all over the world have struggled to respond to the HIV/AIDS epidemic. In 2005 almost 3 million people died because of AIDS, and an estimated 4.1 million acquired the human immunodeficiency virus (HIV) - bringing the number of people living with the virus around the world to about 38.6 million. Almost two thirds of all persons with HIV live in sub-Saharan Africa (1). For many years AIDS is the leading cause of death in this region. In the past decades the life expectancy in sub-Saharan Africa dropped with no less than 15 years, from 62 to 47 years.

South Africa is in the midst of a catastrophic AIDS epidemic; it has the highest number of people living with HIV in the world. End 2005 an estimated 5.5 million South Africans were living with HIV, the overall HIV prevalence among pregnant women was almost one third, about 320,000 people had died because of AIDS, and over a million children had been orphaned (1). To reduce the spread of HIV, the South African government and international aid organisations are investing significant prevention resources in voluntary HIV counselling and testing (VCT). The South African government has established more than 450 VCT centres with more than 800 counsellors around the country (2). Research has shown that VCT can reduce high-risk sexual practices and can decrease rates of sexually transmitted infections (3, 4). In addition, VCT is necessary for directing HIV infected people to highly active antiretroviral therapy (HAART), which is becoming increasingly available in South Africa. In 2001 partners within the Joint United Nations Programme on HIV/AIDS (UNAIDS) and other organisations, along with scientists at WHO, calculated that under optimal conditions 3 million people living in developing countries could be provided with antiretroviral therapy, and could have access to medical services by the end of 2005. Universal access to antiretroviral therapy for everyone who requires therapy according to medical criteria opens up ways to accelerate prevention in communities in which more people will know their HIV status – and, critically, will want to know their status. As HIV/AIDS becomes a disease that can be both prevented and treated, attitudes towards AIDS will change, and denial, stigma and discrimination may rapidly be reduced (5).

There has been growing support and demand for HIV voluntary counselling and testing services that foster risk-reduction behaviour based on knowledge of HIV status and link HIV-infected individuals with care and support services. There are several compelling arguments for HIV VCT: (a) individuals have a right to know their infection status to protect themselves and others from infection, (b) HIV VCT may enable people to cope with the anxiety associated with the uncertainty of not knowing one’s HIV status, (c) early detection of HIV may improve the medical and psychological support for HIV-infected persons, and (d) HIV VCT has been shown to promote safer sex (6).

Determinants of VCT

In order to promote HIV VCT, many studies have tried to unravel the psychosocial correlates of HIV testing. Studies among homosexual men in Western countries revealed that HIV testing was associated with self-perceived risk or health status and attitudes towards testing (7-11), past health service use (9,10), perceived stigma (9, 12-14) and fear of test results (8, 9, 11). The more people think that they might have contracted HIV, the more they acknowledge the advantages of testing and the more familiar they are with using healthcare services, the more likely it is that they will go for a test. The more people fear negative test results and social stigma, the less likely is it that they will go for a test.

Although research on the correlates of HIV testing among non-Western populations (or populations in developing settings) is sparse, these findings are echoed by studies among populations in South Africa. Peltzer, Mpofo, Baguma and Lawal found that among university students in four African countries attitudes towards HIV testing was positively associated with having had an HIV
test, self-rated HIV knowledge, the number of sex partners in the past 12 months, and personally knowing someone with HIV or AIDS (15). In their study among mine workers Day and colleagues found that health concerns were the main motivator to have an HIV test, while fear of test results and the potential consequences, particularly stigmatization, disease and death, were the main barriers. Interestingly, only 14 percent indicated that they would be more likely to access VCT if antiretroviral therapy would become available (16). A study by Kalichman and Simbayi among inhabitants of a black township suggested that AIDS-related stigma is one of the most important barriers for HIV testing (17). Their study showed that individuals who had not been tested for HIV and those tested but who did not know their results, held significantly more negative testing attitudes than individuals who were tested and knew their test results. Compared to people who had been tested, people that were not tested for HIV reported significantly greater AIDS related stigma, ascribing greater shame, guilt, and social disapproval to people living with HIV. To conclude, stigmatization seems one of the main barriers of HIV testing in South Africa.

**AIDS related stigma**

Many have described the HIV/AIDS epidemic as an epidemic of ignorance, fear and denial leading to stigmatization of and discrimination against people living with HIV/AIDS and their family members (18, 19). Stigma refers to any attribute or characteristic of a person that is deeply discrediting. This attribute is devalued in a particular context, and calls into question the full humanity of this person. Persons are devalued, spoiled or flawed in the eyes of others because of this negatively valued attribute and dehumanisation, threat, aversion and social rejection are openly behavioural manifestations of stigmatization (20, 21). Besides of the social consequences, stigma also has detrimental consequences for psychological well-being (22). In addition to stigmatisation at the individual level, stigma can appear in different contexts at societal and community levels. For instance, stigma may lead to restrictions on international travel and migration, mandatory testing for work permits, pre-employment screening, discrimination by health care systems, exclusion from schools, and violence toward so-called high-risk groups (19, 23, 24).

Several factors have been identified that determine stigmatising reactions towards PLHA (people living with HIV/AIDS). First, perceived contagiousness of the disease is related to feelings of fear and stigmatization. Second, perceived seriousness of the disease is related to stigmatization. Third, perceived responsibility for becoming HIV infected is associated with stigmatization of PLHA. And fourth, negative reaction towards PLHA often symbolizes negative attitudes towards groups associated with HIV/AIDS, such as men having sex with men, commercial sex workers, and drug users (25-29). To date, relative few studies have investigated determinants of AIDS related stigma in sub-Saharan countries. These studies suggest that similar determinants are involved (30, 31), although their manifestation may be somehow different. For example, whereas in Western countries AIDS is often associated with homosexuality, in sub-Saharan countries it is associated with other norm violating sexual behaviour, e.g. prostitution. In addition to the determinants that are also found in Western countries, in sub-Saharan countries religious factors and some cultural specific factors also seem to be related to AIDS-related stigmatization (30).

Stigma is still the most important issue that hinders HIV prevention. Fear of being identified with HIV often keeps people from seeking to know their HIV status, discussing prevention, changing unsafe behaviour, and supporting care for PLHA. Stigmatization thus threatens the utilisation and effectiveness of HIV/AIDS prevention and care efforts. Stigma and discrimination also increases the pain and suffering of PLHA and their families (26).

**The present study**

The present research investigates psychosocial correlates of voluntary counseling and testing, with an emphasis on the association between fear of stigma and willingness to have an HIV test. More specifically, the aim of this study is to identify factors that facilitate or impede HIV VCT, and factors that are related to fear of being stigmatized because of HIV/AIDS. The study was conducted by means of focus group discussions (FGD), which provided insight in the cultural-specific correlates of HIV VCT and fear of AIDS-related stigma.

**Methods**

**Participants**

The study was conducted among university students of the University of Limpopo (UL), Polokwane, South Africa. This group is a sexually active target population and is relatively easy to reach. Ten focus group discussions were held among students to explore correlates of VCT and fear of stigma and discrimination. In total 72 black students (35 men and 37 women) of the UL participated. They were undergraduate (62) and postgraduate (10) students, varying in different grades. All students, except one who was married, were single and they were between 18-36 years of age ($M = 21.56$, $SD = 2.96$). They belonged to different ethnic groups, but most of them were Sotho or Tsonga.

**Measurement**

A qualitative study design was chosen to explore the correlates of VCT and fear of stigma.

Students were asked about their HIV/ AIDS knowledge and underlying factors (transmission, ways of protection, consequences of being HIV positive/ negative). Also, their VCT knowledge was asked including benefits and barriers to go for testing. To stimulate group discussion, facilitators told ‘stories’ to which students could react. The stories were used so that the students could replace themselves in the person in the story, to give an accurate opinion. In these stories the themes of stigmatization and VCT came across.
Procedure

Participants were recruited by means of posters, announcements on the university radio station and recruitment by research assistants and peer educators. Potential participants were informed about the content of the group discussion and study procedures, and they were asked to sign a consent form. They were promised anonymity and confidentiality. Ten focus group discussions were conducted in 3 male groups, 3 female groups and 4 mixed groups. Before the discussion started, students were asked to complete a short survey addressing demographics, such as sex, age, ethnic background, and marital status. Each focus group discussion consisted of 6-10 students who discussed various topics. Three interviewers conducted the group discussions: one facilitating and leading the group discussion, the other two were making notes and confidentiality. The group discussions took about one hour, they were audio taped and spoken in English. In order to make the participants feel comfortable in the discussion, a native speaker was chosen to lead the group discussion. At any point in time, when a participant found it difficult to express him/herself in English, he or she could easily switch into the native language. Students were not paid for participating in the group discussion.

Ethics Approval

Ethical approval for the study was obtained from the ‘South African Universities Vice Chancellors Association’ (SAUVCA), which is the national association of South Africa’s twenty-one public universities’.

Analysis

Before analysing the data of the FGD and the interviews, all audiotapes were transcribed. The results of focus group discussions were analysed with QSR NVivo®1.3, a program for the analysis of qualitative data (32). In QSR NVivo® the discussions and interviews were arranged in categories and subcategories (nodes and sub-nodes). The following categories were used to analyse the data: Knowledge of HIV/ AIDs and VCT, AIDS-related stigmatization, and perceived benefits and barriers to go for VCT.

Results

Stigma manifestations

Our FGD clearly acknowledged that there is still a strong HIV/AIDS-related stigma in South Africa. Most participants agreed that PLWA are neglected, ignored and isolated. For instance, participants frequently mentioned that it would be very difficult to get a job when you are HIV positive, that many men leave their women when she is HIV positive, that even family members frequently blame their relatives for contracting HIV/AIDS, and that many PLWA are rejected by friends because people do not want to be associated with someone with HIV/AIDS (33). The FGD also revealed that participants were struggling with HIV/AIDS-related stigma themselves. Although many acknowledged that PLWA should not be stigmatised and discriminated, they recognized that they themselves were also not free of stigmatising reactions (30). For example, one boy remarked:

I tried to accept. And the others, they wanted to give her a life, but this was happening: we are living in front of her and we knew she wasn’t sleeping around, but at the end, she wasn’t accepted anymore, she was just banned out of the family.

Causes of stigma

Ignorance, threat and contagiousness. Although VCT becomes increasingly available nowadays in South Africa (1), at the time of the study antiretroviral drugs were still unavailable in Limpopo province and participants in all FGD still strongly associated HIV/AIDS with ‘dying’ and ‘death’. During the discussions HIV/AIDS was frequently described as ‘the disease that cannot be cured’ or ‘another international death sentence’. Many participants expected that HIV infection would end all their future plans, and some thought that they might commit suicide when tested HIV positive. Only a few participants believed that HIV is not immediately causing death and that it can be possible for PLWA to live a rather normal life.

Our FGD further revealed that participants were seriously concerned about contracting HIV/AIDS. Although they recognised that their beliefs about HIV prevalence at the University campus was based upon rumours, they assumed that about half of the students might be HIV positive. This is illustrated by the following comments of a girl:

I just heard that there are many students infected with HIV. But I don’t know who, I don’t know, I have never met anybody.

Many researchers have argued that the life-threatening character of HIV/AIDS and the perceived contagiousness of the disease are related to stigmatizing responses (26, 27, 30). The participants in our FGD generally seemed to be quite knowledgeable about HIV/AIDS, in particular about various medical aspects of HIV/AIDS and about the major modes of transmission (34, 35). However, our FGD also clearly revealed some serious misunderstandings regarding transmission through casual contact. For example, the majority of participants thought that they could contract the virus by eating food prepared by PLWA. Interestingly, participants revealed mixed feeling regarding sharing things, such as a spoon, mug or a toilet and regarding casual contact like shaking hands and hugging. Although the majority did not believe that one could contract HIV/AIDS by means of casual contact with PLWA, they frequently revealed to fear HIV transmission through causal contact.

Because of the life-threatening character of the disease and misunderstandings about its contagiousness, people generally tend to feel rather uncomfortable about having contact with an HIV-infected person and to cut off contact with the HIV-positive (36). Most participants in our FGD endorsed that they usually feel rather uncomfortable when they anticipate to have, or actually
have, contact with PLWA. They even indicated to feel uncomfortable when they suspect people to be infected. For instance, they stated that they would not go to a bar with HIV-positive bartenders, and that they would not want to share blankets or sheets with someone who is HIV positive. Even participants being aware of the impossibility to contract HIV through casual contact mentioned that they continued to have doubts and behaved as if transmission through casual contact was possible.

Research on social stigma has shown that onset controllability is one of the most important determinants of stigmatization (25, 26, 29). Our FDG confirmed that PLWA are generally held personally responsible for contracting the disease. According to the most participants it is people’s own fault to become infected. They mentioned that HIV/AIDS is usually associated with adultery and unsafe sex with multiple partners. One male participant expressed this clearly:

They are punishing you because you slept around. And people don’t understand why you had that much intercourse.

Correlates of VCT attendance

Several studies have shown that young people are generally not motivated to attend VCT services and that there is a range of barriers varying from availability of services, worries about confidentiality, inaccurate risk perceptions, fear of being stigmatized and perceptions of the consequences of living with HIV (11, 16, 37-40). Many of these barriers were discussed in our FGD.

According to our participants, fear of knowing your positive status is the main barrier to go for VCT. All claimed to be too scared to have an HIV-test because of the risks they might have taken in the past. Many expressed that it is better to be unaware of your HIV status, so that you just can go on with your life and do not have to face the fact that you will die young. Many participants mentioned that life is easier when you ignore the disease and the risks you are running (35). Participants also frequently mentioned that they would only go for VCT when they would feel very sick. As long as there’s no direct and serious physical cause, there is no reason to go for VCT. One male participant expressed very clearly the fear of knowing your status:

Not knowing my status is better. Knowing it makes me anxious. It is better not to know.

Another female participant also indicated that it is better to ignore the disease:

I don’t want to die young. Nothing is better than not knowing. I want to live and don’t worry.

The above-mentioned reactions are in line with theory about stress and coping (41). Since people see a positive test result as a death sentence and a cause for social isolation and rejection, a positive test result causes stress that can only be reduced by defensive coping mechanisms since treatment is still unavailable.

A second major barrier for VCT was the fear of negative social reactions when tested positive, especially from their family. Most participants expected that their family would not react very nicely, and that it would be very likely that they would be rejected and excluded by their family after HIV disclosure. In addition, the participants also feared the reactions of their friends. Most expected that their friends would react in a negative way, and that their friends would not like to be associated with someone who is HIV positive. One male participant expressed the social exclusion of persons with HIV very clearly:

To be honest, other people will start rejecting you. You’re not longer a person, you’re going to die.

A female participant summarized the importance of social stigma in VCT attendance concisely:

As long as there’s stigma, people won’t go.

A third barrier to VCT that was frequently mentioned in our FGD was the distrust in the health care workers of the VCT services. Participants expected to be blamed by the health care workers in case of a positive test result. For example, one girl said:

When they discover that you are positive, they start you to say: Oh, positive! They just start to blame you. While you are still there, they you just look at it and use their own language. The immune system, oh, oh, it’s 18, or what. They are talking about you.

Moreover, participants they had serious worries about the confidentiality of VCT and feared that test results would be shared with the community. In addition, some participants questioned the capability of the health care workers to do adequate testing. These concerns are reflected in the following remark of a female participant:

The nurses who are working there are injecting that person, and some believe that they inject people with the virus. Many people believe that.

Whereas our participants discussed a broad range of reasons not to attend VCT, remarkably few reasons to attend VCT were mentioned in our FGD. According to our participants, the most relevant reason to go for VCT would be severe health complaints. Girls did mention pregnancy as a strong motivation for VCT. For example, one female participant said:

For me now I think it is not so important, but if I get pregnant I would go for protecting my baby.

Other reasons to go for VCT that were mentioned are marriage, a new relationship, having had unsafe sex, having a friend with HIV or job circumstances. These findings are in line with the results of other studies (6, 38, 40, 42, 43). If there was a ‘proper medication to treat people’, people would be more willing to go for a test, while ‘protecting yourself’ and ‘do not infect others’ were
also mentioned as factors to test. The latter findings were not reported in previous research.

Discussion

South Africa is in the midst of a huge AIDS catastrophe: it is estimated that 5.5 million South Africans are infected with HIV (1). Many people do not know their HIV status, which contributes to the further spread of HIV and hampers HIV-infected individuals to start with treatment. VCT is necessary for detecting people’s HIV status and for directing people to antiretroviral therapy, which is becoming increasingly available in South Africa. Despite the fact that a large part of the population is HIV infected, people with HIV/AIDS are confronted with strong stigmatization and social rejection. Fear of becoming stigmatized seems to be a major obstacle for people to go for a HIV test and to get to know their status.

The aim of the present study was to investigate psychosocial correlates of VCT, with a strong emphasis on the relation between fear of AIDS-related stigma and willingness to have an HIV test. The results clearly demonstrated that AIDS is still an epidemic of ignorance, fear and denial. Participants indicated that PLWA are victims of huge discrimination and experience social isolation. Furthermore, participants reported that they do not want to be seen as friend or relative of somebody with AIDS, because they fear to become stigmatized themselves. This so-called stigma by association (33) illustrates that fear of stigmatization is deeply rooted in South Africa. The present research was conducted among university students, who generally belong to the most well-informed groups in our society. It can be expected that stigmatizing responses among other groups in South African society are even stronger.

In line with previous Western research on determinants of AIDS-related stigmatization (21, 25-27), it was found that the life-threatening and contagious character of the disease is related to stigmatization. Participants associated AIDS with death and dying, and had unrealistic risk perceptions about contracting the disease in casual contact. Another important determinant of stigmatization reactions was victim blaming. PLWA were held responsible for their HIV infection and their HIV infection is often associated with immoral behaviour. Victim blaming is also found as an important determinant of AIDS-related stigma in Western societies, although the manifestation of immoral behaviour is somewhat different due to differences in affected populations. In Western societies AIDS is often associated with homosexuality, whereas in South Africa AIDS is strongly linked with promiscuity.

Fear of stigmatization may be one of the most important barriers to VCT uptake. Participants were afraid to become rejected by family members after disclosure of their serostatus. This illustrates the importance of family bonds in South African society. Furthermore, participants indicated that people gossip about HIV-positive people. An important related issue was the lack of trust in health care workers. Participants were afraid to become stigmatized by health care workers and mistrusted their confidentiality.

Previous research among homosexual men has demonstrated that fear of a positive test result is an important determinant of VCT (8). The present study demonstrates that fear of knowing your status is also an important determinant of VCT among South African students. Participants were scared to get a positive test result, because they were aware about the risks they had taken in the past. A positive test result would confront them with a life threatening and stigmatizing disease. A number of participants engaged in denial. They preferred to be unaware of their HIV status and to go on with their lives. Perceived benefits to go for VCT were primarily related to treatment and prevention. Participants indicated that they could start with antiretroviral treatment, as soon as they know their status. Furthermore, pregnancy was often mentioned as a reason for VCT.

The present study investigated AIDS-related stigma and other factors related to VCT among a sample of South African students of the University of Limpopo. This is a sexually active population in a rural area with a large number of HIV infected people. It should be noted that our sample, which consisted of higher educated people, reported strong stigmatizing responses. Future research, however, should also focus on other relevant groups in South African society, especially lower educated persons. In the present study we used a qualitative research design, which offered us the possibility for a thorough and detailed analysis. In future research, however, the present findings should also be replicated in quantitative research. This would allow us to measure the relative impact of all determinants on VCT uptake.

The results of this study have important implications for VCT. Participants have no trust in health care workers and fear that they will inform others about their serostatus. Thus, it seems very important to guarantee anonymity or confidentiality. Nakashima and colleagues found in an American study that HIV reporting by name had no effect on the use of testing and counselling programmes (44). The present study, however, shows that the issue of anonymity and confidentiality is very important in South Africa and prevents people from going for VCT. Furthermore, our study shows that participants also mistrust health care workers’ skills to do adequate testing. It seems very important to negate these perceptions and to restore trust in the health care system. As long as people mistrust health care workers’ skills, people will hesitate to go for an HIV test and health care workers’ counselling will sort limited effects.

AIDS-related stigma is deeply rooted in South Africa and people are very afraid to become stigmatized. Fear of stigmatization is an important barrier to HIV testing and has negative consequences for AIDS prevention and treatment. It is important to educate people about AIDS-related stigma and to design theory- and evidence based interventions to reduce AIDS-related stigmatization (45-47). Such interventions should move beyond the individual level to be effective, and should also target the reduction of stigma at the organizational and community level (19).
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References

5. WHO. The 3 by 5 initiative. Available at: http://www.who.int/3by5 [accessed 22 May 2007]
9. Myers T, Orr KW, Locker D, Jackson EA. Factors affecting gay and bisexual men’s decisions and intentions to seek HIV testing American J Pub Health 1993;83:701-4

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