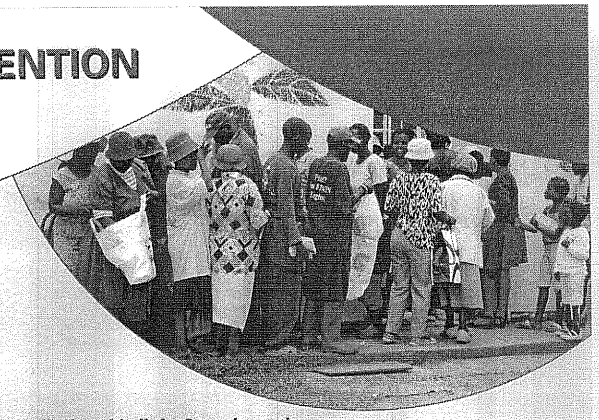
THE PERCEIVED RELEVANCE OF HIV/AIDS PREVENTION AND CARE PROGRAMMES FOR REDUCING VULNERABILITY IN COMMUNITIES



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5th SAHARA Conference, 30 November - 3 December 2009, Gauteng, South Africa

BACKGROUND

Many HIV interventions are being implemented but little is known about their perceived usefulness from a community perspective. This study explored community and key informant's perceptions of HIV and AIDS interventions and assessed their potential for reducing vulnerability to HIV infection in KwaZulu-Natal, South Africa.

METHODOLOGY

- 4 key informant interviews (KII) and 4 focus groups discussions (FGD)
- 84 participants - senior HIV/AIDS programme staff, and community members
- Rural and urban areas in KwaZulu-Natal with different levels of social deprivation
- Transcripts were transcribed, translated and analysed using thematic analysis

FINDINGS

Changes in understanding and behaviour regarding HIV
Respondents reported a positive shift in attitudes of those affected by HIV/AIDS. More support and care is being provided where disclosure has occurred.

> *"I think families are now beginning to support each other. When we first started ... it was very difficult to talk about AIDS. I'm sure you saw this morning most people were just open. No one wanted to [talk before],. So people are really changing"* (Rural KII, KZN)

> *"So they all went and did HIV tests just to check themselves. So now ... they know they could live even if they are positive. ... So in fact, what happened to the first family members has helped them to go and look for help and find ways of dealing with the disease as early as possible"* (Rural FGD, KZN)

Regarding antiretroviral treatment (ART), people are beginning to understand the issues and the importance of getting treated.

> *"ARVs are changing the way people see HIV/AIDS. People in the community who are taking ARVs are well so this can help break stigma"* (Rural KII, KZN)

Coping with HIV
People living with HIV and AIDS face many challenges including disclosure, treatment, stigma and discrimination.

> *"People are coping badly - they don't want their children around us. It's very difficult; no one wants to be around us anymore"* (Urban FGD, KZN)

> *"Those who are involved with AIDS awareness programmes, or in support groups, they live much better because they share all their pains and stories. So the more they empower others they relieve stress"* (Rural KII, KZN)

Why Prevention programmes are not working
Respondents said that target groups for which the programmes are designed do not understand the content of the messages.

> *"Communities have not been consulted. The community is not taken into consideration. They need to talk to ordinary folk. When a tool of prevention is designed it is done in an office, but should deal with the normal layman on the street. Strategies are not effective. They are not appealing to people on the street. They are keeping people vulnerable"* (Urban KII, KZN)

> *"I think they are not working very well, ... I think the main problem is that the community leaders were not involved initially with setting up. As a result there is this tension between government programmes, NGOs and community leaders. They always ask: who are you? How did you know to come up with these strategies or why are you doing these things? Whereas if the community leaders were initially involved with ... these programmes, then the running of these programmes would be much more effective"* (Rural FGD, KZN)

People's vulnerability to HIV
Findings suggest that gender and power dynamics, as well as ignorance and denialism play a role in the spread of HIV among communities.

> *"I think gender still plays a huge part - you know for women. Kind of not having power, not having that equal kind of footing you know. And I think that just plays itself out"* (Rural FGD, KZN)

> *"People don't believe the disease really exists. Indians are in denial and believe that only blacks get the disease. Many are infected but they don't take the disease seriously. They see it as another kind of sickness"* (Urban FGD, KZN)

Poverty and unemployment
Findings show that the widespread unemployment and related poverty was made worse for many by HIV and AIDS.

> *"I think it's poverty, poverty, poverty. No matter how we could try to tackle the issues of AIDS and crime, if we don't deal with poverty it will be a problem"* (Rural FGD, KZN)

> *"My husband died and he was the breadwinner in the family, I do not work and cannot find a job, I collect government grant but that is not enough, I buy food and the money is finished, I have no extra money to go to the clinic, taxi fees are expensive and I cannot afford it"* (Rural FGD, KZN)

Traditional and cultural beliefs: Sexual practices
Some respondents felt that the culture condoned multiple concurrent partners. Polygamy was singled out as an area of concern.

> *"The Zulu tradition is to have many wives and we need to change this. Need to teach people to have one sexual partner. Changing traditions takes a long time but it is a starting point. It is all about education - focusing on the right things and people, for example, monogamy"* (Urban FGD, KZN)

> *"I speak from outside of the culture of polygamy but it has to be re-examined in a completely changing environment"* (Rural FGD, KZN)

Traditional and cultural beliefs: Delay in starting antiretroviral treatment
Preference for traditional healers was implicated as a cause of late presentation and poor adherence to ARV therapy.

> *"There is also a tendency for them to start with a traditional healer and then go to the clinic, which delays ARV access"* (Rural KII, KZN)

> *"She wasn't taking ARVs and got worse. But after some time she went to the clinic. At the clinic they gave her ARVs and she's much better now. She's healthy and she thinks that ARVs helped her more than taking the traditionalist/herbalist stuff"* (Rural FGD, KZN)

Poor treatment at clinics: Fear of disclosure and breach of confidentiality
There was a distinct theme around the inability of health services to maintain confidentiality for those seeking HIV and AIDS care.

> *"I mean one of the things they were saying was every clinic has a prevention kind of section where people who are HIV positive get tested. Nobody wants to go there because you're treated from the start as if there's something wrong with you. You have to go into this little room - regardless of whether you come out negative or positive, everyone's assumed that you are positive and people are not wanting to go and get tested simply because they know they'll still be judged..."* (Rural, FGD, KZN)

> *"It should be treated like other disease, because once you have a special unit for HIV/AIDS it becomes obvious, its separates people. Whereas if it was treated maybe just like diabetes or blood pressure it would be much better"* (Rural FGD, KZN)

RECOMMENDATIONS

Issues needing to be addressed: Government and Private sector
Suggestions to improve the response to HIV/AIDS for reducing vulnerability in communities included:

- Government must increase expenditure with regard to NGO support.
- The private sector is not involved enough but they could be a huge resource in terms of time, finances, resources and information.

Respondents also wanted programmes tailored to specific population groups and for role models within these communities to dispel the myths around HIV and help address stigma and discrimination.

> *"Would be useful to use infected people to help, who can share a testimony and say 'I've been there, I know what it's about'. We need support groups and counseling, people need a sense of belonging and a feeling of being loved, spirituality also helps this pandemic"* (Urban FGD, KZN).

> *"Need to deal with different issues in different areas. For example, African people are shown in posters - this creates a misconception that the disease only affects blacks. The material needs to be localized"* (Urban FGD, KZN)

Challenges experienced with governmental assistance:
Respondents from NGOs said government assistance to them was poor. Problems ranged from limited resources to delays in service delivery, with regard to both health services and financial assistance.

> *"Government makes all these fancy policies, which is all good and nice, but they do not come to the grass roots and see if it is really working, clearly its not. People should go into communities to see what's happening before they make all these policies"* (Urban KII, KZN)

> *"Government is always geared in preventing from grassroots level before combating it. 'Prevention is better than cure'. But, government is not doing one tenth of what it should be doing"* (Urban KII, KZN)

CONCLUSION

Key informants felt that there are signs of improvement with people becoming more willing to talk about HIV and AIDS. The message that ARVs can make a difference is beginning to get through and makes people more willing to seek help. However, the perceptions of community members were frequently negative with strong opinions expressed about the lack of understanding of local issues by those developing policies and interventions.

HIV and AIDS intervention programmes need to engage communities to ensure that the information is locally relevant and understood by the target audience. Stigma needs to be addressed before messages regarding HIV prevention and transmission are likely to be accepted.

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The perceived relevance of HIV/AIDS Prevention and Care Programmes for Reducing Vulnerability in Communities

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Abstract

Background: The South African National Strategic Plan for HIV & AIDS and STI calls for an intensified, comprehensive, multi-sectoral, national response. Many interventions are being implemented but little is known about their perceived relevance or usefulness from a community perspective.
Aim: This study explored community and key informant's perceptions of current HIV and AIDS interventions and assessed their potential for reducing vulnerability to HIV infection in selected rural and urban communities in KwaZulu-Natal, South Africa.
Methodology: Four key informant interviews were conducted with senior staff in government and non-government HIV and AIDS interventions, and eight focus group discussions were held with community members in areas where these interventions were being implemented. The interviews and discussions explored perceptions of HIV/AIDS prevention and care programmes.
Analysis: Transcripts were transcribed, translated and analysed using thematic analysis assisted by the software package Atlas.ti.
Findings: Target groups for which the programmes are designed apparently do not understand the content of the messages. "*Communities have not been consulted. The community is not taken into consideration. They need to talk to ordinary folk. When a tool of prevention is designed it is done in an office, but should deal with the normal layman on the street. Strategies are not effective. They are not appealing to people on the street. They are keeping people vulnerable.*" (Key informant Chatsworth, KwaZulu-Natal).
Conclusion: HIV and AIDS intervention programmes need to engage communities to ensure that the information is locally relevant and understood by the target audience. Stigma needs to be addressed before messages regarding HIV prevention and transmission are likely to be accepted.

Keywords: Prevention, stigma, HIV, AIDS, ARVs, coping, vulnerability, community development.