

Understanding Barriers to Community Participation in HIV and AIDS Services

Summary Report

**Population Council
Health Systems Trust**



The
ATLANTIC
Philanthropies

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Acknowledgments

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Introduction

In 2003 South Africa announced its intention to rollout what is possibly the largest HIV and AIDS treatment program in the world. Much attention is currently being focused on supply side issues, particularly on the procurement and pricing of drugs. Far less attention has been paid to the equally important issues around the demand for and delivery of treatment, care, and support services. Further, although the role of the community and community organizations is articulated in government policy there has been little active engagement with non-governmental organizations (NGOs) on the development of these roles or on how to encourage community support and participation in the antiretroviral (ARV) rollout.

This study was conducted to collect data on barriers and challenges to the use of services and on the involvement of community organizations in HIV and AIDS and ARV services for use in the design and implementation of appropriate interventions. The specific objectives of the study, implemented by the Population Council in collaboration with Health Systems Trust and with support from Atlantic Philanthropies in 2005–2006, were to:

- Improve understanding of the context of the utilization of public health HIV and AIDS services, including antiretroviral therapy (ART) and entry points to treatment such as voluntary counselling and testing (VCT).
- Assess the role that communities and community-based organizations (CBOs) can play in the implementation of the government's HIV and AIDS treatment and care plan for the ARV rollout.

Background

In November 2003, the South African Government released its national treatment plan (Mbewu 2003). The initial goal of the plan was for at least one service delivery point in each district to provide AIDS treatment by the end of the first year (2004). This target was subsequently revised to be realized by the end of 2005.

Treatment sites were identified and inspected under the auspices of the Department of Health (DOH) based on a set of minimum criteria. To meet requirements, in addition to medical considerations, sites needed to have a full range of community support services including counseling, adherence support, community mobilization, home and community based care, and palliative care. Key challenges for implementing the treatment plan included: strengthening existing programs that provide entry points to treatment (VCT, preventing mother-to-child transmission [PMTCT], TB programs), building strong partnerships between health facilities and community support structures, and obtaining good patient information.

It is estimated that approximately 4.84 million people are living with HIV in South Africa (Department of Health 2006). Between 500,000 and 700,000 people are thought to be in need of treatment. In March 2006, a report by the AIDS Law Project found that 110,000 people were receiving ART through the public sector and that a further 90,000 people were receiving it through the private sector (Joint Civil Society Monitoring Forum 2006). Therefore roughly 27–38 percent of those in need of treatment are receiving it.

When service use is disaggregated by province, the highest enrollment figures are in Gauteng, the Western Cape and KwaZulu Natal. Overall, far higher numbers of women are accessing treatment than men, likely both because of higher infection rates and higher use of public services including antenatal care (ANC). Children make up about 10 percent of all individuals receiving treatment. Only about 10,000 of the estimated 50,000 children in need of treatment are receiving it (International Treatment Preparedness Coalition 2005).

In 2005, the South African Government's budget for HIV and AIDS (including treatment) was R1.5 billion, and by the end of the year 204 health facilities were providing ART. All 53 health districts have at least one health facility providing treatment and 63 percent of the 252 subdistricts in the country have a rollout site. There are 54 operational sites in KwaZulu Natal's 11 districts, while in Limpopo there are 23 operational sites in the 6 health districts (Department of Health 2006).

SUMMARY REPORT

Many of the necessary ancillary services and entry points to treatment are provided by community-based organizations. Home-based care (HBC) services will play a key role in identifying clients in need of ART, and in monitoring adherence and side effects among those already receiving it. TB services using community run directly observed therapy (DOT) programs also need to have strong links to the treatment program. VCT is another key program to provide education on and create demand for treatment. Community mobilization can contribute substantially to the rollout. Successful mobilization ensures adequate support for people living with HIV, combats stigma and discrimination, reduces social isolation, increases adherence, and contributes to the success of community education programs (WHO 2004).

Methodology

For the study, four areas in the provinces of KwaZulu Natal and Limpopo were selected. One urban and one rural community or municipality was chosen in each province for the study. These were:

- Maphumulo municipality in Ilembe district in KwaZulu Natal (rural)
- Chesterville in eThekweni (Durban) municipality, KwaZulu Natal (urban)
- Sekhukhune in Makhuduthamaga local municipality in Limpopo (rural)
- Polokwane Municipality in Capricorn district in Limpopo (urban)

Table 1. Summary of HIV prevalence rates in KwaZulu Natal and Limpopo in population sub-groups

Population	KwaZulu Natal %	Limpopo %
ANC clients	41	19
Adults (ages 15–49)	16	12
Youth (ages 15–24)	8	6

Sources: DOH 2004; and Shisana et al. 2005

Qualitative research methods were used to generate data on social norms and attitudes as well as to provide insight into the socioeconomic and cultural context of behaviors. The project sought to generate a rich body of findings from a smaller number of respondents rather than less detailed information from a larger group. The sample frame consisted of health care workers at clinic and hospital level, community workers, people living with HIV, traditional healers, community leaders, NGOs and CBOs in the geographic area, clinic committees, support groups, and community members who were not affiliated to any particular group or organization. A total of 284 people were interviewed. While the findings from the research may not be representative or generalizable, they indicate areas for further exploration and contribute to the development of site-specific strategies that may have wider applicability in similar contexts.

The following research activities were conducted:

- Identification of community leaders and stakeholders in each community.
- Preliminary meeting held with groups representative of community members and service providers to introduce the project.
- 23 focus group discussions (FGDs) conducted to identify community needs and priorities and social, cultural, and structural determinants/barriers to access to a variety of treatment and related services affecting different groups of service users.
- 13 FGDs/in-depth interviews conducted with community stakeholders including community leaders, traditional healers, faith healers, and religious leaders to identify community needs and priorities and determinants/barriers to access to a variety of treatment and services.
- 35 FGDs and key informant interviews conducted with program managers and staff, including volunteers, of NGOs, CBOs, faith-based organizations (FBOs), and AIDS organizations on the services delivered and perceived/potential capacity of the organization.
- Documentation of current community programs relating to the delivery of treatment services.

- Assessment of the capacity of community organizations to represent communities, to participate in structures, and to provide feedback to their constituencies.
- Participatory workshops held in each site to disseminate the findings and to explore the potential role of NGOs, FBOs, and CBOs in the rollout of treatment.
- Strategy development meeting held nationally to discuss implications of the research findings and to map out intervention strategies.

Permission to conduct the study was obtained from the University of Witwatersrand Ethics Committee. Ethical approval was also received from the Population Council. In addition, it was necessary to obtain permission from the Department of Health to conduct the research in Limpopo and KwaZulu Natal.

Key Findings

Communities aware of HIV and AIDS, but need more information

Communities appeared to be familiar with HIV and AIDS, the burden of the disease and its consequences. Respondents cited feeling powerless and overwhelmed by HIV and AIDS. Although some basic information on HIV and AIDS was available, frequent references to low levels of access to appropriate information on HIV and AIDS were made. In addition, illiteracy was cited as a barrier to successful community education in rural areas since most educational material is produced in print form.

There is poor communication in terms of disseminating the information on HIV and AIDS to this community. Most of the people are illiterate, both adult and young people. They find difficult to use pamphlets and posters. There are many posters here but it doesn't serve the purpose. The only effective way to communicate with the community is to have campaigns with the community and talk about HIV and AIDS.

—Deputy Chairperson of the Maphumulo AIDS Council

The prevalence of HIV and AIDS was acknowledged in all sites and there was general consensus that youth are the most affected by the epidemic. However respondents cited a significant number of myths regarding transmission of the disease—particularly in one rural site. These misconceptions range from beliefs that HIV was invented by the apartheid regime to suspicions that HIV is a punishment from God.

My attitude changed when she explained that you don't contract HIV through sexual intercourse only but there are many ways of contracting HIV virus. I remembered a verse from the Bible that says if people don't believe in God he will send an incurable disease. I think this is the disease that He was talking about.

—Participant of ARV class, Maphumulo

Many people interviewed indicated that the introduction of ARVs was a positive development that has played a key role in containing the virus. However, equally, there were people who viewed ARVs with suspicion and skepticism. While levels of information on the existence of ARVs tended to be higher in urban areas, no significant differences in the views expressed on ARVs were detected by province or site.

I have a cousin who was very sick and she went on ARVs. She is now so healthy that if you compare her to me you would think I am the one who is ill because she looks much healthier than me.

—Community leader, Sekhukhune

Most of them believe that ARVs are killing people. They think that once you start ARVs you will die very soon.

—Member of Youth NGO, Maphumulo

SUMMARY REPORT

Stigma barrier to HIV and AIDS care, treatment, and prevention

Stigma, which exists at both household and community levels, is a key barrier to HIV and AIDS care, treatment, and prevention programmes in all research sites, and its impact on social support systems and the psychological well-being of people living with HIV is pervasive. People living with HIV reported difficulty disclosing their status due to fear of stigma and discrimination. Disclosure of status was often linked to advanced stages of AIDS with some people disclosing their status just before death. Further, uptake of and adherence to treatment was often compromised due to fear of discrimination.

I know of a case where cruel things happened where a TB/HIV patient was closed indoors and nobody went into that room because they said the individual will infect them. Even when they gave such a person food they opened the door slightly and put the food on the ground. Even windows were closed because they were scared that they would be infected. They even refused when visitors came into the room and they said visitors would depress the patient further.

—Youth, Chesterville

In all sites, stigma was also reported to be strongly associated with visiting certain health facilities, including VCT and ARV treatment sites. Fear of stigma and discrimination deterred people from testing and consultation, resulting in a delay in knowing one's HIV status and the initiation of treatment. Disclosure within the community was often indirect, e.g., food parcels and feeding formula obtained from the clinic were seen as strong indications of an HIV-positive status. Community members in all sites reported informally diagnosing people with HIV based on physical symptoms and other signs. Diagnostic criteria included weight loss, rashes and hair loss.

When one is HIV-positive they have to eat healthy food and there is a yellow maize meal that is specially made and distributed through the clinic to HIV-positive people. We usually detect someone's HIV status by these food parcels that they carry into their home from the clinic. The majority of community members don't disclose on their own.

—Male, Polokwane

In addition, specially allocated VCT and HIV and AIDS treatment rooms may further prevent uptake of treatment for fear of being identified as HIV-positive. In some instances a lack of space reportedly compromised the confidentiality of VCT and acted as a deterrent to testing and counselling. There also appeared to be reluctance among people to use services where local community members were employed for fears that the confidentiality of their status would be compromised.

I was scared to be seen by people because most of the people who are working here are our neighbours.

—PLHA, Maphumulo

The nurses who are working here are gossiping about people who come to the hospital. They even mention a person's name if they are talking. They say we saw so and so at hospital s/he was checking that thing.

—PLHA, Maphumulo

There is no privacy as the VCT room is right in the middle of the clinic. It is very uncomfortable, as people in the clinic will see all the people who go into the VCT room after which they will gossip and say, 'Did you see Mr. So and so coming from the VCT room?'

—Community leader, Sekhukhune

Families both stigmatize and support PLHA

Family members and outside caregivers generally supported people living with HIV. Stigma and discrimination appeared to be less prevalent in cases where people had first hand experience of a loved one suffering from HIV and AIDS. In some cases families were willing to care and support people living with HIV but insisted that affected family members keep the disease a secret from the community.

Community Participation in HIV and AIDS Services

It's actually the support I that I received from my family more than anything.... After testing positive I told him (her partner). He also went for a test and we both support each other.... His support really helped me.

—PLHA, Polokwane

Some families don't even want us as caregivers to visit patients in their households. They actually chase us away. They would rather hide the patient and deny the status of the patient until the patient dies. Our success stories are therefore equal to our failures.

—HIV-positive caregivers, Polokwane

People living with HIV related a wide variety of experiences ranging from rejection and ill-treatment to acceptance and support. They also played an important role in breaking down stereotypes and motivating other people living with HIV to disclose their status.

Teaching families is important because it makes it easier for people to disclose to their families. If families can understand that HIV-positive people are not abnormally sick, they are just like people who have diabetes or cancer.

—Community health worker, Chesterville

Traditional healers play important role in HIV and AIDS management

Consultation with traditional healers featured as a common recourse for relief in times of ill health. Most respondents reported seeking assistance from both traditional healers and allopathic medical practitioners although the order of consultation varied. In general, respondents in urban sites tended to visit allopathic healers at the nearest clinic before seeking the help of traditional healers. Patterns of consultation also varied according to age group with younger respondents preferring local health services to traditional healers.

In this community most people are consulting traditional healers. I think people need to be educated about health because they consult traditional healers first. They consult hospitals when their situation is worse which make very difficult for doctors and nurses to help.

—Patient advocate, Maphumulo

The reason for them to consult traditional healers is that traditional healers are in the community compared to the money they spend on transport to hospital. There is a mobile clinic, which comes once a month, and it does not come if it is raining. It is something you cannot rely on.

—Community member, Maphumulo

There are these traditional healers who say they cure HIV/AIDS and people believe those stories.

—Church leader, Chesterville

The apparent tension between Western medical practitioners and traditional healers has been well managed in some sites where traditional healers organized themselves into formal groupings and have provided training (in collaboration with the local DOH) on management of HIV and AIDS to their members. In some sites, cooperation between the two parallel systems existed with traditional healers recommending that clients visit local health centers when an HIV diagnosis is suspected and providing home based care for HIV patients.

We were taught about AIDS prevention and signs of HIV. We are now aware that people sometimes have hallucinations when they are HIV-positive. Nowadays we don't interpret hallucinations as ancestral visitations, we refer people to the clinic to be tested for HIV when they present with hallucinations.

—Traditional healer, Sekhukhune

SUMMARY REPORT

Poverty and dependence huge concerns for communities, people living with HIV

High levels of poverty and unemployment characterized all sites. Most people reported having experienced food insecurity on a regular basis and basic services (such as water) were often unaffordable or non-existent. Respondents also cited illiteracy as a problem in their communities and social security grants—in particular the disability grant, was often reported as the only source of income in a household.

Households in receipt of social grants can make strategic choices about accessing health services as managing transport and other costs becomes easier. Some respondents have reported borrowing money from informal money lenders in anticipation of receiving a social grant in order to access services.

However, the requirement that those wishing to access a social grant must be in receipt of a 13-digit identity document causes much hardship to applicants. Respondents frequently described their experiences trying to access identity documents and birth certificates from the Department of Home Affairs as time consuming, expensive, and protracted.

Disability grants were also a major concern for people living with HIV. Large numbers of those ineligible for grants had no other source of income. Using CD4 counts as eligibility criteria for accessing grants precludes many from receiving desperately needed funds and may have several negative effects on treatment and prevention efforts. These include poor nutrition and resultant poor health outcomes for people living with HIV and lack of access to services, which potentially increases drop out rates and the number of adherence defaulters. Conversely, some people may use services opportunistically to access grants.

When I was there the sister that helps us told me that my CD4 count are higher and I'm not qualify for the grant as I wanted to fill the form for the grant that is received by people living with HIV. I asked her why we are not qualified as we are HIV-positive and how will we maintain our life because they say we must eat healthy food, but we don't have the money.

— Person living with HIV, Maphumulo

One community health worker reported that there is one man who said he is on ARV treatment. The man said his interest is the grant. Family members are not sure if he takes the treatment.

— Social worker, Maphumulo

Youth and women particularly vulnerable to HIV

Despite a plethora of information and messages on prevention of HIV and on reduction of high-risk behaviours, youth are still perceived as engaging in high-risk behaviour. A reluctance to use condoms by youth was reported in all sites. Reasons reported include embarrassment asking for condoms, lack of information on how to use them, the perception of reduced sensation when using condoms, and women refusing to use condoms in order to become pregnant to access the child support grant. Youth reported difficulty in speaking to their parents about issues related to sex and HIV and AIDS while parents felt that these issues should not be discussed outside the home.

When we teach about HIV in schools, a lot of parents come to us and they complain that we are discussing sexual issues with their children and they say they don't want their children to discuss sexual issues with anybody.

— Clinic sister, Sekhukhune

We know how they work but the problem is that when young people are drunk they don't use the condoms even if they have them.... Parties and drinking, going to shebeens, because people get exposed to rape in such situations and they forget to use condoms and youth actively engage in all the activities mentioned.

— Youth, Polokwane

Community Participation in HIV and AIDS Services

Women experience HIV and AIDS at a multitude of levels. Entrenched patriarchy and poor socioeconomic conditions make women particularly vulnerable to infection. Since they feared being blamed for infecting their partners, some women reported keeping their HIV-positive status secret from their husbands, often out of fear of violence or abandonment.

But he (the woman's partner) doesn't know she is HIV-positive. She didn't tell him...because he could kill her. He still behaves very old fashion...the only person who knows is her daughter.

—Person living with HIV, Maphumulo

There is a woman who tested positive and she told her partner. Her partner left the house since that day and never came back. He left her with children. He didn't even tell her where he was going.

—Social worker, Maphumulo

Moreover, women were also responsible for guarding against MTCT, caring for people living with HIV, and acting as primary caregivers of children whose parents have died of AIDS.

I live with my mother who is sick and a small child and my sister's child who is also sick. I don't have people to share my problems with. There are times when I don't know what to do. It is very tough for me as I am alone a lot of times.

—Woman living with HIV, Maphumulo

Male migrant workers and the practice of polygamy were also seen as contributing to the epidemic. Further, rape and transactional sex, which was mentioned in the urban sites, suggests that women do not always have the power to negotiate the use of condoms with partners.

Rape of small children by relatives is a problem in our area. Men don't work and when the females in the family go out to seek employment they stay at home and start to rape children. Relatives such as their uncles rape about children who are about 3 years or 5 years.

—Woman, Polokwane

I have seen a case where different men everyday pick one girl at 4.00 p.m. The girl sleeps during the day and starts to bath and go out at 4.00 p.m. everyday with a different man. These are the type of things that spread HIV/AIDS.

—Male, Polokwane

Numerous barriers to treatment include transport costs

Most people expressed the view that accessing ARVs is extremely difficult and expensive. Barriers to treatment mentioned included lack of money and food, transport difficulties, having to make too many arduous trips to health facilities, adherence training, poor treatment by health facility staff, inability to apply without a 13-digit bar-coded identity document, long delays between application and receiving treatment, and extensive waiting lists.

She went there for a CD4 count. When she was supposed to collect the results she was very sick and her sister went there to collect the results but they refused to give her the results. They said they wanted her to collect her results. She died after that because she was unable to walk. We had no transport to help her to collect her results.

—NGO staff member, Chesterville

Knowledge about eligibility criteria for ARVs was uneven. People living with HIV, those on ARVs, and health care workers tended to have more information about eligibility criteria than ordinary community members. However, this information was not always accurate or complete. Most people, for example, were aware of the CD4 cell count eligibility determinant, but only one or two people mentioned the World Health Organization's (WHO) staging criteria.

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Most HIV-positive respondents reported that the travelling costs associated with accessing treatment and care were prohibitive. Transport related barriers to accessing health services were mentioned at both the clinic and hospital level—with the latter posing significantly more problems because they are fewer in number and generally situated in towns or cities. There was a general perception that the health care centres that provided ARVs were situated too far away and were thus inaccessible. People used a variety of means to travel to the clinic and ARV health facilities—these ranged from walking, taking taxis, hiring private cars and in some extreme cases, using wheelbarrows. The poor condition of roads exacerbated difficulties travelling to health centres especially in rainy weather.

A person needs to take transport to get there. If one does not have bus fare, that would mean s/he would not get his/her treatment in time. The person has not started getting this grant and family members cannot help because they can't afford.

—Community health worker, Chesterville

The transport costs involved in attending ART literacy programmes together with a patient supporter was also cited as being a deterrent to the uptake of ARVs. Being in receipt of a disability grant appeared to render transport costs less onerous.

Sick people don't have money for transport when they have to collect treatment. If you go there you need transport money and you need to buy something to eat. If you haven't got your grant you will go to the money lender.

—Person living with HIV, Chesterville

Paediatric treatment viewed as challenging for multiple reasons

Many of the people living with HIV interviewed had children. Some respondents recounted how their infants and young children had died before treatment was widely available.

Getting children enrolled on ARVs is challenging owing to a number of reasons. Pediatric treatment tends only to be available only at tertiary hospitals and there is limited expertise in treating children at public health facilities. It is encouraging to note that the study was able to find children enrolled in the treatment program in KwaZulu Natal.

He was diagnosed HIV-positive long time (ago) because of many illnesses that is why he delays to take treatment.... He was on treatment for a long time for TB and pneumonia. He just started ARV treatment on Thursday.

—Grandfather of an 8-year-old, Maphumulo.

Barriers preventing children from accessing treatment included lack of identity documents, poor links to PMTCT programs, HBC and orphans and vulnerable children (OVC) programs, and lack of human resources. Many of the models of providing treatment and supporting people on treatment are based on adults rather than on the needs of children. An additional problem highlighted by the research is the challenge faced by elderly caregivers in supporting children on treatment.

Health facilities face staff, space, and equipment shortages

All sites indicated that human resources shortages were experienced at the health facility level. These shortages referred to nurses, doctors, community health workers, counsellors and home-based caregivers. Infrastructural constraints included old, dilapidated or insufficient equipment and a shortage of space. These issues tended to feature more prominently, although not exclusively, among health facility staff rather than by users of the clinics.

Shortage of staff is a problem in our clinic. We also have shortage of space.

—Clinic sister, Polokwane

Community Participation in HIV and AIDS Services

Respondents in one province indicated that they were not always treated well by clinic and hospital staff and some suggested that they were discriminated against as a result of their status.

At clinic they treat us very bad like if we ask something they say we didn't send you to get this disease. We don't get good treatment at the clinic.

—Person living with HIV, Chesterville

Some comments suggested that health facility staff did not always understand patients' difficulties in keeping appointments. A number of respondents felt that they were not always given information about their health and reported being sent to various different places for a variety of tests. Comments about rude treatment from staff were noticeably absent in Limpopo Province. Reasons for this may include the existence of more organised functional clinic committees in Limpopo, which might have contributed to better staff attitudes and client relations in the province.

Adherence and nutritional support for people living with HIV limited

The introduction of treatment in the public sector has raised concerns about adherence. In order to address adherence and prevent resistance, all people living with HIV receive adherence training prior to starting ARVs. In order to be eligible for treatment, people living with HIV are also required to disclose their status to a treatment supporter, usually a family member, who is also required to attend the training with them to gain information on side effects and their management. All those on treatment reported minor side effects but found them manageable. However, it is likely that our sample over represented people living with HIV who had already been successfully enrolled and treated.

The findings indicate that a limited range of adherence strategies was employed. From a facility perspective, adherence support consists of training people living with HIV and their supporters, issuing medication in monthly or bi-monthly quantities requiring repeat visits to collect medication and counting dosages dispensed. People living with HIV reported receiving reminders from treatment supporters and alarms to take daily doses. Additional community support through patient advocates or treatment supporters was limited due to a lack of NGO/CBO resources and staff for this purpose and low levels of disclosure.

No one follows up, however to me this is not a problem, as I believe that my health is my responsibility. I am not worried if they don't check on me as I can still look after myself. They check and count the pills before you get them.

—Person living with HIV, Maphumulo

They give an allowance of two days for the next visit before the pills get finished... to make sure that I don't finish the pills before the next visit'. Initially when I started she [her sister] would call me every morning at 8 a.m. to remind me as she works in town. At half past 8 at night she called me and in the evening when my father was back from work he also reminded me. At Hope Centre they actually encourage us to buy cell phones in order to set alarms so that we don't forget to take our medication.

—Person living with HIV, Polokwane

Inadequate nutritional support was being provided to people living with HIV with the majority only receiving nutritional advice. Some people living with HIV received nutritional support in the form of supplements or food parcels, which in some cases was limited to the supply of porridge. In many cases there was ad hoc or inconsistent support. People living with HIV in all the sites felt that they were not able to follow the advice on nutrition provided at clinics and hospitals. Lack of food and resources seemed to play a role in poor adherence and poor uptake of treatment services. Little nutritional support beyond counseling and education was available either from government departments or NGOs and CBOs.

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One of my clients fails to take treatment because she didn't have food. I went to the hospital to report the case. You can take treatment before meals, but you must eat something later...that person has nothing at all. We then organized food parcels for her and she continued with her treatment.

—Patient advocate, Maphumulo

Many people living with HIV (on and off ARVs) took a wide variety of supplements to boost their immune systems. Both people living with HIV and stakeholders reported that homemade supplements were being used in addition to what was commercially available.

There are people taking traditional herbs and immune boosters from Golden Products. Others they know they will not cope with adherence with treatment and for that reason they prefer to take immune boosters.

—Social worker, Maphumulo

Despite limited resources, people living with HIV found ways to purchase these supplements and considered them important to their health. Some were using immune boosters as an alternative to ARVs, citing the inability to adhere to ARVs and fear of side effects as reasons for why they chose immune boosters instead.

Community involvement with HIV and AIDS issues varied

There were low levels of broad community involvement in HIV and AIDS issues, although pockets of activism existed in all sites. This activism took the form of support groups, home-based carers, fostering, clinic committees and community health workers. Roles tended to be filled mainly by women on a volunteer basis without remuneration. In all sites, there were signs that HIV and AIDS is starting to find its way onto the agenda of other mainstream community activities, such as in churches, school, and community meetings.

The community is not active enough in HIV activities it would be good to see more people involved the problem is that people are not free to talk about the problem of HIV.

—Community leader, Maphumulo

With the exception of a few CBOs that are predominantly involved in providing home based care, community members did not report close links with NGOs working in the area. Respondents in all sites were skeptical of NGOs and suggested that that they did not always work in the best interests of the community, and that they were fragmented and did not work together. At the same time, all sites identified NGOs as having a critical role to play in supporting treatment initiatives and in educating communities on HIV.

NGOs must stop to misusing funds and work and deliver to the people. If NGOs can work together maybe we won't have problems.... There is lot of white people in NGOs and there are very few black people. White people come in our communities with projects. We don't know where they get money from. They come with very little help and take photos. We need NGOs that are from the community because they will have their sympathy with these people rather than a person from outside whose interest is on money. If NGOs can sit together and make one proposal I think that will have good results.

—Chairperson of CBO, Chesterville

Despite some initiatives, community involvement was beleaguered by a host of challenges including lack of leadership, lack of credibility and the fact that many people still needed to be convinced of the dividends of community involvement. Given the stigma associated with HIV, community involvement might result in secondary stigmatization. There were few positive examples of community involvement in the area of HIV and AIDS for people to draw on.

Support groups were widely considered beneficial in assisting people living with HIV to cope with the burden of the disease. However, there were challenges to establishing support groups, retaining members, and sustaining groups in areas where resources are limited and the disease remains highly stigmatized.

Community Participation in HIV and AIDS Services

I tell people that I am HIV-positive and answer all their questions about HIV. People in my community welcome me and I don't feel snubbed by anybody. I answer their questions as much as possible and I think its part of education to my community on issues related to HIV.

—Person living with HIV on treatment, Sekhukhune

I get a lot of support from the HIV support group we have in our community...in the support group we are able to share our problems and we help each other. The support group is very useful as we are all HIV-positive and understand each other's problems.

—Person living with HIV, Maphumulo

Sometimes I meet people who are HIV-positive in the clinic but they don't want to talk about it so the tendency is to keep to ourselves as we want confidentiality...people hide the fact that they are HIV positive...it is therefore difficult to form a support group.

—Person living with HIV, Maphumulo

Home-based care programmes were a main source of care and support for people living with HIV and their families. Levels of training were varied and remuneration scales remained uneven and dependent on irregular donor and government funding. In some cases, the caregivers in this sector were purely volunteers and living with HIV themselves, and they often faced the same challenges as they people they assisted.

We look after terminally ill patients and we don't only look after HIV-positive people we also look after old people who are unable to look after themselves and we also help orphaned children and disabled people.

—Home-based caregiver, Sekhukhune

We need a small stipend that could assist us to travel to some of the places where assistance is required. We are poor people who don't even have enough food to eat therefore it would be helpful to receive a little money that will assist us.

—Home-based caregiver, Sekhukhune

Community health workers are intended to play a significant role in the rollout of treatment and care for people living with HIV. However, there have been challenges regarding role confusion, lack of training, and building and maintaining relationships with NGOs and health facilities and home-based carers. Given the large catchment areas they serve, their presence in communities varied from being seen as the only source of support for people living with HIV to been seen as non-existent.

There are community health workers that are working in our communities. They visit our houses but they don't talk about HIV/AIDS. They check if children have gone to immunization and they also check if we are using clean toilets.

—ARV class, Maphumulo.

As community health workers, we have not been given training on ARVs, whereas people ask us, as they know that we are community health workers. Then you find that we do not know as well.

—Community health worker, Chesterville

The only people helping in this community to deal with this situation are community health workers even though they are not enough to deal with this situation. We still need more community health workers because this community is very huge.

—Community leader, Maphumulo

Clinic committees are a strategic entry point in developing community participation in health care services, and HIV and AIDS issues in particular, and are legislated for in the National Health Act. Despite this, clinic

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committees have not flourished and there was a wide range of opinions on their roles and function. Where functional, they have played a significant role in education on HIV and AIDS and have facilitated dialogue between the community and health centers.

If we find that the place is dirty we clean the place and if there is no food we follow up with social welfare through the clinic. We have a clinic garden where we take vegetables if someone is hungry and we cook for them. We provide community health on behalf of the clinic and this is part of the terms of reference of the clinic committee. Sometimes we provide assistance in the clinic by having health desks and here we mobilize the community by encouraging them to use the clinic. For instance we encourage mothers to keep coming for growth monitoring by showing the importance of bringing children for growth monitoring.

—Clinic committee, Polokwane

The clinic committee is a link between the community and the clinic and we as clinic committee members look at the manner in which nurses attend to the community and we assist by looking at people who desperately require assistance and oversee the general cleanliness in the clinic and ensure that the cleaning are available and that they actually perform their duties in time.

—Clinic committee Polokwane

Recommendations

To generate recommendations, respondents were asked about potential strategies various role players could employ to address the barriers to the ARV rollout identified. Participants identified a range of actions the government, NGOs and other community organizations, health facilities, and other community actors could take to address the community and facility-level barriers preventing the uptake and use of HIV-related services. Recommendations were developed from the participant feedback, as well as from trends identified by the researchers in the study findings. While the recommendations are based on the experiences of the four study sites, many of the strategies have wider applicability at both the policy and program level.

Because of high levels of illiteracy and misconceptions, messages contained in posters and pamphlets must be augmented by in-depth discussions about HIV and AIDS at the community level. The use of respected community stakeholders to deliver messages about HIV and AIDS in a wide range of contexts should be explored.

Raising awareness of the existence of stigma in the community, explaining its causes, and the various forms in which it is manifested is crucial to reducing its presence. People living with HIV and AIDS have an important role to play in encouraging disclosure, reducing stigma, and serving as trustworthy sources of information and positive role models for communities. Responsible and sustained political leadership and direction is also needed.

Educational activities need to be scaled up in order to address traditional beliefs that prevent people from seeking appropriate medical interventions for urgent health problems and from using remedies that are harmful. Collaboration between traditional healers and Western medical practitioners is increasing and should be further promoted. Traditional healers must receive training and information on HIV and its management, and ways to encourage partnerships between the two health systems need to be explored.

NGOs and CBOs have a crucial role to play in providing information and training on ARVs. Target audiences include the broader community, traditional healers, health facility workers, religious and traditional leaders, and local organizations such as women or youth groups. Training should include information on treatment centers, eligibility criteria, adherence, side effects, and healthy living.

Community Participation in HIV and AIDS Services

Community based organizations and NGOs have an important role to play in facilitating access to social security grants at the local level. CBOs and NGOs can act as a bridge between government departments, such as the Department of Home Affairs and Department of Social Development, and lobby for speedy processing of applications and the acceptance of alternative means of identification when applicants have difficulty providing the required documentation.

Strategies to address high-risk behaviour among youth must be developed. A strategic entry point for interventions is schools and other places where youth gather. Interventions should include education and training on the correct use of condoms. Forums and groups for youth to discuss their sexuality, among themselves and with parents and other community members, in a safe non-judgmental environment must be created and sustained. This is especially needed in rural areas where social taboos prevent such discussions. Counseling and rehabilitation services for youth to curb alcohol and substance abuse are also needed.

Poverty alleviation and food security programmes that target women may reduce their dependence on men and subsequent vulnerability to HIV infection. Aggressive, culturally acceptable gender awareness programmes must be carried out at local levels in order to dispel many of the myths which perpetuate gender-based violence and discrimination against women.

Plans must be made to fast track the delivery of ARVs at the primary clinic level. Districts must ensure that NGOs and CBOs are involved in the delivery of treatment at community level. Community level meetings to discuss how best to ensure collaboration between the health service, community and NGOs and CBOs are recommended to inform the process of greater involvement by the community and NGOs.

The public health sector transport programme must be revitalised. Additionally, innovative ways must be found to provide affordable and reliable transport to people wishing to access health care services—especially from clinic to hospital level. One possible alternative would be to explore the potential to form a public-private partnership with existing taxis in the area.

Efforts are needed to support those caring for HIV infected individuals. Stakeholders recommended that educational activities need to focus on family members as caregivers for those affected by HIV, as this would assist in destigmatizing the disease, capacitate caregivers to provide care and support, and increase community support for people living with HIV. Efforts to increase access to treatment will also eventually reduce the burden on caregivers if more HIV-positive people remain well and able to care for themselves.

Given that many people living with HIV live in relative poverty, strategies to improve their nutritional status are needed. More needs to be done in terms of establishing the efficacy of immune boosters. A cost-benefit analysis of the usefulness of various commercially available products may assist people living with HIV in deciding how best to use limited resources. Strategies to reduce the cost of commercially available supplements may be needed if they are proven efficacious in improving the immune status of people.

Given the South African Government's endorsement of the use of traditional medications, more effort needs to be invested in establishing the benefits and risks of their use. The government may need to regulate the sale and use of supplements. An unintended consequence of the current information strategies on adherence, such as those emphasizing 100 percent adherence, may be to discourage people from taking ARVs. A balance needs to be found between promoting ARVs and informing people of the potential dangers and side effects of treatment. Strategies to increase treatment promotion and support may address this issue.

There is a need to strengthen PMTCT programs including addressing issues around infant feeding, HIV diagnosis in infants and the follow up of women after PMTCT. Treating mothers may also assist in ensuring that HIV-positive children remain in the system and are treated if necessary. Ongoing efforts to enrol children on ARVs are needed in the South African context, particularly in rural areas and in lower prevalence provinces because of low enrolment rates of children in these areas. Further exploration is needed into how access to treatment for children and providing support to children on ARVs can be promoted and facilitated.

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Addressing barriers preventing children from accessing treatment should be prioritized. Better links between HBC and OVC programs and treatment programs are also needed.

Strategies are needed to increase the accessibility and uptake of support group services. Successful models need to be documented and disseminated. Alternative locations for support groups may increase the uptake of services. Similarly, linking support groups to the distribution of food parcels and income-generating activities may also increase their uptake and make them more sustainable. The role of support groups in promoting adherence needs to be explored further.

Steps to facilitate community involvement in HIV and AIDS services must be locally driven. NGOs have a role to play in assisting communities to identify their strengths and available resources as well as areas of need. Resources need to be allocated to drive the process. Transparent and credible mechanisms such as forums for dialogue and discussion between stakeholders and role players must be created at local level. Finally, successful models of community involvement must be disseminated and popularized.

To advocate for greater and effective community involvement in the national ARV program, these recommendations were shared with key local, provincial and national stakeholders at a workshop held in June 2006. In addition further dissemination meetings are planned in the four study sites to refine strategies and to develop appropriate community based interventions.

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