

ABSTRACT

This chapter highlights some of the findings of a qualitative research study which was undertaken in four areas in the provinces of KwaZulu-Natal and Limpopo. The study collected information on some of the critical barriers to community participation in HIV and antiretroviral services. One urban and one rural community or municipality was chosen in each province for the study.

Respondents included health care workers at clinic and hospital level, community workers, people living with HIV, traditional healers, community leaders, non-governmental organisations and community based organisations in the geographic area, clinic committees and support groups.

Findings indicate that poverty and stigma operate as significant barriers to accessing HIV and AIDS care and treatment services in the public health sector. Women and youth face particular challenges in participating and accessing services and bear a disproportionate burden of the HIV epidemic. Socio-economic constraints (e.g. travel costs) coupled with perceptions that access to treatment is fraught with difficulties and delays were cited as compelling barriers at facility level which impact on uptake of treatment. Human resource shortages contribute to the poor acceptability and responsiveness of health services. Social security for people living with HIV is inequitable and the current eligibility criteria for disability grants can result in unintended outcomes. Nutritional support and food insecurity have a powerful impact on adherence and treatment stability. Sustained gains in broadening access to treatment and care are likely to remain elusive without the full support and participation of communities. NGOs have a key role to play in assisting communities to identify their strengths and available resources as well as areas of need. Transparent and credible mechanisms such as forums for dialogue and discussion between communities and other stakeholders must be created at local level. Finally, successful models of community involvement must be disseminated and popularised.

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INTRODUCTION

In 2003, South Africa (SA) announced its intention to roll-out what is possibly the largest HIV and AIDS treatment programme in the world.¹ It is estimated that approximately 5.54 million people are living with HIV in South Africa.² Between 500 000 and 700 000 people are thought to be in need of treatment. In March 2006 a report found that 110 000 people were receiving antiretroviral therapy (ART) through the public sector and that a further 90 000 people were receiving it through the private sector.³ Therefore roughly 27-38 per cent of those in need of treatment are receiving it.

When service use is disaggregated by province, the highest enrolment 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 sector services including antenatal care. Children make up about 10 per cent of all individuals receiving treatment. Ten thousand of the estimated 50 000 children in need of treatment are receiving it.⁴

In 2005, the South African Government's budget for HIV and AIDS (including treatment) was R1.5 billion, and by the end of that year 204 health facilities were providing ART. All 53 health districts have at least one health facility providing treatment and 63 per cent of the 252 sub districts in the country have a roll-out site.²

Many of the necessary ancillary services and entry points to treatment are provided by community based organisations (CBOs). Home based care (HBC) services 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) programmes also need to have strong links to the treatment programme. Voluntary Counselling and Testing (VCT) is another key programme to provide education on and create demand for treatment. Community mobilisation can contribute substantially to the roll-out. Successful mobilisation ensures adequate support for people living with HIV (PLWHIV), combats stigma and discrimination, reduces social isolation, increases adherence, and contributes to the success of community education.⁵

However, while much attention has been 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 organisations is articulated in government policy⁶⁻⁸ there has been insufficient active engagement on the development and strengthening of these roles or on how to encourage community organisations and stakeholders to support and participate in the antiretroviral (ARV) roll-out.

A research study^a undertaken in four areas in the provinces of KwaZulu-Natal and Limpopo highlights some of the critical barriers to community participation in HIV services. One urban and one rural community or municipality was chosen in each province for the study. The sites are characterised by high levels of poverty and unemployment. Most people experience food insecurity on a regular basis and basic services such as water are often unaffordable or non-existent. There are high levels of illiteracy and social security grants, in particular the disability grant, are often the only source of income in a household.

Qualitative research was undertaken with health care workers at clinic and hospital level, community workers, PLWHIV, traditional healers, community leaders, non-governmental organisations (NGOs) and CBOs in the geographic area, clinic committees, support groups, and community members who were not affiliated to any particular group or organisation.

COMMUNITIES' AWARENESS OF HIV AND AIDS

Communities appear to be familiar with HIV and AIDS, the burden of the disease and its consequences. Although some basic information on HIV is available, there is little access to appropriate information. In addition, illiteracy is a barrier to successful community education in rural areas since most educational material is produced in print form.

a This chapter is based on a research report: Padarath et al. (2006) 'Understanding Barriers to Community Participation in HIV and ARV Services' published by the Population Council and Health Systems Trust.



“There is poor communication in terms of disseminating the information on HIV and AIDS to this community. ... They find it 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 is acknowledged and there is general consensus that youth are the most affected by the epidemic. However, a significant number of myths regarding transmission of the disease persist. These misconceptions range from beliefs that HIV was invented by the apartheid regime to suspicions that HIV is a punishment from God.

The introduction of ARVs is viewed as a positive development that has played a key role in containing the virus. However, equally, there is suspicion and scepticism. While levels of information on the existence of ARVs tend to be higher in urban areas, there are no significant differences in the views expressed on ARVs.

“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

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

STIGMA BARRIER TO HIV CARE, TREATMENT, AND PREVENTION

Stigma, which still exists at both household and community levels, is a key barrier to HIV care, treatment, and prevention programmes, and its impact on social support systems and the psychological well-being of PLWHIV is pervasive. PLWHIV continue to report difficulty in disclosing their status due to fear of stigma and discrimination. Disclosure of status is often linked to advanced stages of HIV-related illnesses, with some people disclosing their status just before death. Further, uptake of and adherence to treatment is 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

Stigma is strongly associated with visiting certain health facilities, including VCT and ARV treatment sites. Fear of stigma and discrimination deter people from testing and consultation, resulting in a delay in knowing one's HIV status and the initiation of treatment. Disclosure within the community is often indirect, e.g., food parcels and feeding formula obtained from the clinic being 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 respondent, Polokwane

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

“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 can 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

Family members and outside providers of care and support services generally care for PLWHIV. Stigma and discrimination appear to be less prevalent in cases where people have first hand experience of a loved one suffering from HIV. In some cases although families care for and support PLWHIV, they insist that affected family members keep the disease a secret from the community.

“It’s actually the support 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.”

Person living with HIV, Polokwane

TRADITIONAL HEALERS PLAY IMPORTANT ROLE IN HIV MANAGEMENT

Consultation with traditional healers features as a common recourse for relief in times of ill health, with many people seeking assistance from both traditional healers and allopathic medical practitioners although the order of consultation varies. In general, respondents in urban sites tend to visit allopathic healers at the nearest clinic before seeking the help of traditional healers, and younger people appear to prefer the use of local health services over traditional healers.

“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

In some sites traditional healers have organised themselves into formal groupings and have provided training (in collaboration with the local Department of Health) on management of HIV to their members. There is also evidence of cooperation between the two parallel systems with traditional healers recommending that clients visit local health centres when an HIV diagnosis is suspected, and providing HBC 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

POVERTY AND DEPENDENCE HUGE CONCERNS FOR COMMUNITIES, PEOPLE LIVING WITH HIV

Disability grants are a major concern for PLWHIV. Large numbers of PLWHIV not eligible for grants have 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 PLWHIV 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 PLHA. 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

YOUTH AND WOMEN PARTICULARLY VULNERABLE TO HIV

Despite an abundance 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 with a reluctance to use condoms. There is embarrassment about 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 have difficulty in speaking to their parents about issues related to sex and HIV while parents feel 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

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

"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 are also responsible for guarding against mother-to-child transmission (MTCT) of HIV, caring for PLWHIV, and acting as primary caregivers of children whose parents have died of HIV-related illness.

"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

TRANSPORT

Most people expressed the view that accessing ARVs is extremely difficult and expensive. Barriers to treatment include lack of money and food, transport difficulties, having to make too many difficult 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

Travelling costs associated with accessing treatment and care are considered prohibitive at both the clinic and especially the hospital level. There is a general perception that the health care centres that provide ARVs are situated too far away and are thus inaccessible. The transport costs involved in attending ART literacy programmes together with a patient supporter are also a deterrent to the uptake of ARVs.

PAEDIATRIC TREATMENT

Getting children enrolled in ARV programmes is challenging for a number of reasons. Paediatric treatment tends 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 programme 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 include lack of identity documents, poor links to prevention of mother-to-child transmission of HIV (PMTCT) programmes, HBC and Orphans and Vulnerable Children (OVC) programmes, 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 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 (nurses, doctors, community health workers, counsellors and home based caregivers) are experienced at the health facility level. Infrastructural constraints include old and dilapidated facilities, insufficient equipment and a shortage of space.

Patients are not always treated well by clinic and hospital staff and some report discrimination against them arising from 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

Health facility staff do not always understand patients’ difficulties in keeping appointments. The existence of more organised functional clinic committees in Limpopo, which might have contributed to better staff attitudes and client relations in the province may be the reason for the absence of complaints from patients about rude treatment.

ADHERENCE AND NUTRITIONAL SUPPORT FOR PEOPLE LIVING WITH HIV

The introduction of treatment in the public sector has raised concerns about adherence. In order to address adherence and prevent resistance, all PLWHIV receive adherence training prior to starting ARVs. In order to be eligible for treatment, PLWHIV 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.

However a limited range of adherence strategies is employed. From a facility perspective, adherence support consists of training PLWHIV and their supporters, issuing medication in monthly or bi-monthly quantities requiring repeat visits to collect medication and counting dosages dispensed. PLWHIV may receive assistance from treatment supporters or use alarms as reminders to take daily doses. Additional community support through patient advocates or treatment supporters is limited due to a lack of NGO/CBO resources and staff for this purpose and low levels of disclosure.

“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 8am 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 is being provided to PLWHIV with the majority only receiving nutritional advice. Some PLWHIV receive nutritional support in the form of supplements or food parcels, which in some cases is limited to the supply of porridge. In many cases there is ad hoc or inconsistent support. PLWHIV have difficulty in following the advice on nutrition provided at clinics and hospitals. Lack of food and resources plays a role in poor adherence and poor uptake of treatment services. Little nutritional support beyond counselling



and education is available either from government departments or NGOs and CBOs.

“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 organised food parcels for her and she continued with her treatment.”

Patient advocate, Maphumulo

Many PLWHIV (on and off ARVs) take a wide variety of supplements to boost their immune systems, including home-made supplements.

“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, PLWHIV found ways to purchase these supplements and consider them important to their health. Some use immune boosters as an alternative to ARVs, due to concerns about their ability to adhere to ARVs as well as fear of side effects.

COMMUNITY INVOLVEMENT WITH HIV

Levels of general community involvement in HIV issues are low, although pockets of activism exist. Activism takes the form of support groups, home based carers, fostering, clinic committees and community health workers. Roles tend to be filled mainly by women on a volunteer basis without remuneration. HIV is starting to find its way onto the agenda of other mainstream community activities, such as in church, school, and community meetings.

With the exception of a few CBOs that are predominantly involved in providing HBC, no close links with NGOs working in the area were reported. Instead there is some scepticism about NGOs, with the suggestion that they do not always work in the best interests of the community, even though there is a recognition that NGOs have a critical role to play in supporting treatment initiatives and in educating communities on HIV.

“NGOs must stop 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 is surrounded 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 stigmatisation. Support groups are widely considered beneficial in assisting PLWHIV to cope with the burden of the disease. However, there are challenges to establishing support groups, retaining members, and sustaining groups over time in areas where resources are limited and the disease remains highly stigmatised.

“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

HBC programmes form a main source of care and support for PLWHIV and their families. Levels of training vary and remuneration scales are uneven

and dependent on irregular donor and government funding. In some cases, the caregivers in this sector are purely volunteers and living with HIV themselves, and they often face the same challenges as the people they assist.

“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

Community health workers are intended to play a significant role in the roll-out of treatment and care for PLWHIV. 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 varies from being seen as the only source of support for PLWHIV to being 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 immunisation 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

Clinic committees are a strategic entry point in developing community participation in health care services, and HIV issues in particular, and are legislated for in the National Health Act. Despite this, clinic committees have not flourished. Where functional, they have played a significant role in education on HIV and HIV-related illnesses and have facilitated dialogue between the community and health centres.

“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

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

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.

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. Such 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 their 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. Counselling 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. Effective, 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 partnership with existing taxis in the area.

Given that many PLWHIV live in relative poverty, strategies to improve the nutritional status of individuals are needed. More needs to be done in terms of establishing the efficacy of immune boosters. In addition, a cost-benefit analysis of the usefulness of various commercially available products may assist PLWHIV 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.

An unintended consequence of the current information strategies on adherence, such as those emphasising 100 per cent 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 programmes 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. Further exploration is needed into how access to treatment for children and providing support to children on ARVs can be promoted and facilitated. Addressing barriers preventing children from accessing treatment should be prioritised. Better links between HBC and OVC programmes and treatment programmes 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 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 popularised.

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