Strengthening Community Health Systems: Perceptions and responses to changing community needs

CADRE

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Disclaimer

The views in this report are those of the authors, and do not necessarily represent the views of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
CBO	Community-Based Organisation
CSG	Child Support Grant
DG	Disability Grant
FGD	Focus Group Discussion
HBC	Home-based Care
HIV	Human Immunodeficiency Virus
NAPWA	National Association for People Living With AIDS
NGO	Non-Governmental Organisation
OVC	Orphans and Vulnerable Children
PLHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TB	Tuberculosis
VCT	Voluntary Counselling and Testing

BACKGROUND

This research was commissioned by the Performance Evaluation and Policy Unit of the Global Fund to Fight AIDS, Tuberculosis and Malaria. It follows on a study of the community-level system effects of large scale funding for AIDS conducted in South Africa in 2005 and 2006 and forms part of a multi-year programme of research looking at the challenges of strengthening community systems for responding to HIV/AIDS.

Both the current and previous research activities have been conducted in the same three South African communities – an urban township, a small town, and a deep rural area. This on-going research at community level has allowed for an in-depth understanding of the lived world of HIV/AIDS, and importantly provides a chance to trace changes and trends over time in individual attitudes and perceptions about AIDS, as well as the forms of community activity that have emerged to respond to the epidemic.

The current commissioned research has two components: the first is to explore changes in individual perceptions and attitudes towards AIDS in the three communities, with particular attention to the role of community-level organisations in shaping people's knowledge, attitudes and behaviours; the second is to explore and document models for coordinating and resourcing community-level HIV/AIDS activities that can help to prevent bottlenecks and obstacles to the absorption and use of funding. This report presents findings and discussion related to the first component of the research.

HIV/AIDS IN SOUTH AFRICA

South Africa has a generalised HIV epidemic, with an estimated HIV prevalence rate of 10.8% among the overall population (aged 2 and above).[1] Approximately 5.5 million South Africans are HIV-positive.[2]

Prevalence rates vary significantly by province, type of settlement, age, gender and racial group, with the highest prevalence rates found amount men aged 30-39 (23.3%) and women aged 25-29 (33.3%). KwaZulu-Natal province has the highest HIV prevalence rate (16.5% prevalence among the general population aged 2 and above) and the Western Cape has the lowest, at 1.9%. A prevalence rate of 17.6% was found among residents of urban informal settlements, compared with urban formal settlements (9.1%), rural informal settlements (11.6%) and rural formal settlements (9.9%). Prevalence rates vary by race, with 19.9% of Africans aged 15-49 HIV-positive, compared to 3.2% of Coloureds, 1.0% of Indians and 0.5% of Whites.[3]

1 Shisana, O. et al (2005). *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005.* HSRC Press, Cape Town.
2 National Department of Health (2006). *National HIV and Syphilis Prevalence Survey South Africa 2005*
3 Shisana et al, 2005

Mortality data from Statistics South Africa[4] shows that the death rate for females aged 20-39 tripled between 1997 and 2004, and doubled over the same period for men aged 30-44. HIV-related deaths have a distinct age profile, with the peak deaths for women occurring at ages 30-34 and for men at ages 35-39. HIV is not a reportable disease in South Africa and many HIV-related deaths are attributed on death certificates to other natural causes, such as TB or parasitic diseases. Calculations using year on year mortality data suggest that at least 600,000 South Africans have died of AIDS-related diseases between 1998 and 2003,[5] although the actual number is likely considerably higher.

HIV prevalence and AIDS-related deaths continue to rise in South Africa, despite over a decade of communication campaigns aimed at educating the population about HIV, modes of HIV transmission, and approaches to preventing infection. Large-scale national campaigns run by both government and NGOs have been complemented by more localised efforts in schools, churches, and workplaces. The 2005 prevalence, incidence, communication and behavioural household survey found that implicit knowledge of HIV/AIDS and accompanying behavioural responses (eg. VCT, condom use) is high, confusion about key aspects of HIV/AIDS remains among certain groups. For example, nearly one-fifth of young people aged 12-14 did not understand the sexual transmission of HIV and close to one-third said 'no' or 'don't know' when asked if HIV could be transmitted from mother to child. Approximately one-third of respondents in all age categories disagreed or were unsure if reducing the number of sexual partners could reduce the risk of HIV infection. There was also confusion about whether HIV causes AIDS and whether there is a cure for AIDS.[6]

South Africa has a well-developed condom distribution system and surveys have shown that people believe condoms to be easily and readily accessible. Reported condom use at last sex among young people aged 15-24 has increased over time to current levels of 72.8% among men and 55.7% among women.[7]

The provision of ARV treatment in the public sector is being scaled-up in South Africa, although only a small proportion of South Africans for whom ART is indicated are presently accessing the treatment. ART in the private sector has been available for many years, and a small but growing number of companies provide treatment to their employees. By February 2006, there were 204 public sector facilities that were accredited and functioning as ARV points, including one in each of the country's 53 health districts.[8] It is estimated that more than 200,000 South

4 Anderson, B. & Phillips, H. (2006). *Adult Mortality (age 15-64) Based on Death Nofication Data in South Africa: 1997-2004*. Report No. 03-09-05. Pretoria: Statistics South Africa.
5 Geffen, Nathan. 'What do South Africa's AIDS statistics mean? A TAC briefing paper.' Treatment Action Campaign. Accessed 14 September 2006. www.tac.org.za/aidsstats.html
6 Shisana et al, 2005
7 Shisana et al, 2005
8 SA UNGASS report (2006).

Africans are currently receiving ARV treatment in the public and private sectors combined, although statistics and patient monitoring systems are still evolving.[9]

Information about HIV/AIDS is readily available in South Africa through numerous national and sub-national communication-oriented interventions, and a range of key HIV/AIDS interventions are in place – from a national system for the distribution of free condoms through to the roll-out of ART through the public health system. However, although communication and HIV prevention campaigns have been in place for nearly a decade, HIV prevalence rates have continued to rise, raising questions about both the relationship between AIDS education – which has contributed to increased uptake of services such as VCT, condoms and ART – and socio-economic, biological and other factors which exacerbate spread of the disease.

It is against this backdrop of both systemic change (expanded resources, growing access to treatment) and advances of various aspects of the epidemic (increased awareness and response) that the views of South Africans living in the three study communities are explored.

9 WHO/UNAIDS estimated that 190,000 were on ARVs by the end of 2005. *2006 Report on the Global AIDS Epidemic*.

STUDY OBJECTIVES

The specific objectives of this research were:

- To explore individual attitudes and responses to HIV and AIDS with reference to issues of prevention and personal behaviour, as well as issues of treatment, care, and support;
- To assess changing community needs in relation to HIV and AIDS, including the support needs of individuals and organisations;
- To explore perceptions of the community-level support environment, including HIV and AIDS-related activities being undertaken by community organisations.

RESEARCH CONTEXT

The study was conducted in three sites: a large urban township, a small town, and a deep rural area. The sites are distinct from one another and variations allow for exploration of the research issues within different types of communities.

Grahamstown

Grahamstown is a small town located in Cacadu District Municipality in the Eastern Cape. The larger Grahamstown community (Makana Municipality) has a population of approximately 62,000 people. It comprises the town centre, which is dominated by a business district and university, a well-established suburban settlement and an urban township area stretching over two kilometres beyond. The population of Grahamstown is 78% Black African, 12% Coloured, and 10% White.

Grahamstown is an old town and its townships are well-established. Although some of the housing in the Rhini and Fingo areas was built recently, other buildings date back more than 50 years. Fifty-five percent of people in Grahamstown live in houses with their own yards, 15% live in traditional dwellings and 10% live in shacks or informal houses. There are more households in Grahamstown that use bucket or pit latrines (58%) than have flush toilets.

Twenty-seven per cent of Grahamstown residents (aged 15-65) are employed. Thirty-four percent describe themselves as unemployed or unable to find work.

The HIV/AIDS situation in Grahamstown

The province-wide HIV prevalence rate amongst adults 15-49 years for the Eastern Cape was estimated at 15.5% in 2005.[10] In Makana Municipality, where Grahamstown is located, HIV prevalence among 15-19 year olds using public sector clinics has been estimated at 17%. It is estimated that there are approximately 5,000

10 Shisana, O. et al (2005)

HIV-positive people in Makana Municipality, with 600 of them in the late stages of infection. There are believed to be 500-600 children in Makana Municipality orphaned as a product of AIDS.

Responses to HIV/AIDS in Grahamstown

A community audit of AIDS-related activities in Grahamstown conducted in 2003-2004 identified 67 different organisations involved with AIDS response, including 30 different NGOs, CBOs and FBOs. More than 600 volunteers were affiliated to these efforts.

Some of the major organisations include the Grahamstown Hospice; the Grahamstown Health Forum, which oversees a network of 45 clinic-based caregivers; the Raphael Centre, which provides VCT, counselling, and education, as well as support to vulnerable children. Funding to support these efforts comes from government sources, private foundations and international development agencies, and local businesses.

The ART programme at Grahamstown's Settlers Hospital is one of the most advanced in the province. Approximately 600 people are currently on treatment and there is no waiting list of people eligible, but not able to be admitted because of backlog.

Obanjeni

The Community

Obanjeni is a deep rural area located in the northeast of KwaZulu-Natal. The area falls within the jurisdiction of uThungulu District Municipality and has a population of approximately 8,000-10,000 people. The area is headed by a Tribal Authority under a traditional leader.

The area does not have a clear focal point or geographical 'centre.' There is a general store and a series of scattered homesteads called 'imizi' that comprise the area of Obanjeni. The physical infrastructure in the area is underdeveloped: access to electricity, water and sanitation services is limited. Institutions such as schools, community halls, shops and churches are located at a distance from one another and there are few tarred roads. The closest clinic is in Esingweni, approximately 5km away, and the closest community of size is Mtunzini, which is 6-7km away and separated from Obanjeni by the N2 motorway. The town of Eshowe is approximately 20 kilometres to the west of Obanjeni.

HIV/AIDS in Obanjeni

HIV prevalence statistics are not available at sub-provincial level in South Africa, so there is no way of knowing exact HIV prevalence rates in Obanjeni. However the province of KwaZulu-Natal has the highest HIV prevalence rates in the country – 16.1% among youth aged 15-24, and 21.9% among adults aged 15-49 (Shisana et al, 2005). Obanjeni is an impoverished area with high rates of unemployment, limited

health care facilities and constrained access to other basic services, education and information. It is reasonable to assume that Obanjeni is an area that is heavily affected by HIV/AIDS, yet under-served in terms of response and support.

In the community audit of AIDS-related activities, very few organisations or structures were identified in Obanjeni. The community is served by a local home-based care NGO which receives no outside funding, by a single caregiver linked to a hospice located in Emoyeni (a neighbouring area), and by informal support and outreach projects run by churches in Obanjeni and nearby Mtunzini. Social welfare services for the area are managed out of the office in Esikhawini. Interviews with families and caregivers suggest that fear of stigma prevents many HIV-positive residents in Obanjeni from disclosing their status.

Vosloorus

The Community

Vosloorus is a large urban township in the Ekurhuleni Metropolitan Municipality, located on Johannesburg's East Rand (Gauteng Province). It has a population of approximately 150,000 – 99.8% of whom are Black African. Vosloorus is divided into five electoral wards. Each ward has its own elected councillor who represents the ward at the metropolitan council.

Vosloorus is a well-established township and the majority of its residents live in formal housing – 72% live in brick houses located on individual stands. Most Vosloorus residents have access to water either inside their dwellings or outside in their yards. More than 92% of residents have flush toilets connected to a sewage system.

Despite the presence of basic infrastructure in most areas of Vosloorus, the township also includes a number of informal settlements. The 2001 census found that 6% of the population resides in shacks or informal dwellings. Conditions in the informal settlements are significantly underdeveloped in comparison with the more established areas of the township: roads are not paved, access to water is through communal taps, electricity supply varies, and there is no sanitation system.

Only 36% of 15-65 year olds in Vosloorus are formally employed.

HIV/AIDS in Vosloorus

The province-wide HIV prevalence rate (ages 15-49) for Gauteng Province was estimated at 15.8% in 2005. HIV prevalence among young people in Gauteng aged 15-24 was estimated at 9%. The HIV incidence rate in Gauteng province was estimated at 3.1% – the fourth highest provincial incidence rate in the country.[11] No statistics about HIV prevalence are available at a sub-provincial level, so it is not possible to estimate how many people in Vosloorus are HIV-positive. However, it is

11 Shisana, O. et al (2005)

known that HIV prevalence rates among residents in urban informal settlements are higher than any other settlement type – 17.6% (among the general population two years and older), compared, for example, to 9.1% of residents in urban formal settlements.[12] It is therefore reasonable to assume that HIV prevalence is higher among residents of informal settlements than in other parts of the community.

A community audit of AIDS-related activities in Vosloorus conducted in 2003-2004 identified 104 different organisations involved with AIDS response, including 24 NGOs, CBOs and FBO.[13] The other institutions included government departments, crèches and day care centres, shebeens, shops and hairdressers that distribute free condoms to patrons.

There are approximately a dozen home-based care organisations in Vosloorus that use caregivers to visit HIV-positive people in their homes. There are also two NGOs that run large-scale programmes oriented at supporting vulnerable children through day care activities and food parcels and emergency care. Several of the clinics have support groups for HIV-positive individuals. There are also independently run community initiatives that address the care needs of the elderly and of households experiencing difficulty accessing social grants.

In each of the five electoral wards, there is a ward committee comprised of local individuals who work with the ward councillor on social and developmental issues. The ward-level health representatives are focal points for many of the care and support services available, and ward-level meetings are important venues for sharing information about services with the community.

Methodology

Focus group discussion (FGD) was the primary approach used in this study. In order to achieve variation in terms of age group, occupation/activity, sex, and HIV status the following categories for focus group participants were established:

- Parents – 4 males, 3 females (Obanjeni)
- High school teachers – 4 males, 4 females (Obanjeni)
- PLHA – 3 males, 4 females, 20-30 years (Grahamstown)
- Youth – 3 males, 5 females, 18-25 years (Grahamstown)
- Clinic attendees – 2 males, 5 females, 50+ years (Vosloorus)
- Tavern attendees – 4 males, 2 females, 25-35 years (Vosloorus)

12 Shisana, O. et al (2005)
13 Birdsall, K. & Kelly, K. 2005, Community Responses to HIV/AIDS in South Africa: Findings from a Multi-Community Study.Johannesburg: CADRE

The initial stage of the study included the development of an interview guide, which was pre-tested with a group of youth from a college in Johannesburg. This was transcribed and reviewed, leading to the refinement of the study instrument (Appendix 1).

The FGDs were held in settings that included community halls and schools. Sessions were tape recorded and conducted by experienced facilitators supported by assistants. The discussions were conducted in languages that participants felt comfortable with (including English, Sesotho, Isi Zulu and IsiXhosa). Consent forms were completed as part of the introduction to participation, and discussions took between one and a half and two hours.

All FGDs were tape recorded and transcribed. Transcribed texts were reviewed and themes identified, following which a coding framework was developed. The data was electronically coded using HyperRESEARCH 2.6.

Structure of the Report

This document is structured into two parts. First, key findings from the focus group discussions are presented thematically, beginning with findings related to individual perceptions of and behavioural changes related to HIV and AIDS, followed by material about the community institutions that are involved with HIV/AIDS activities. Second, a discussion section in each identifies important findings and considers them in relation to existing understandings of HIV and AIDS response in the three sites.

FINDINGS

PERCEPTIONS OF INDIVIDUAL RESPONSES TO HIV/AIDS

Individual perceptions, attitudes, and thoughts associated with HIV/AIDS

There is a high awareness of HIV/AIDS in South Africa and this includes a wide range of associated perceptions about the disease. Among focus group participants, the most pervasive association with HIV/AIDS is the fatal nature of the disease.

> *Once people have the disease, I think of death.*[14]
>
> *AIDS is a short cut to heaven.*[15]
>
> *If I have HIV/AIDS then I will die.*[16]
>
> *As for me, when I think about AIDS, I think about a sick person who will not be cured or treated. In the end he will not be cured. He will be dead.*[17]

Fear of death and dying is a common perception, with one participant saying of a person with HIV/AIDS: *"She might not get up the following day, regardless of the fact that she leads a healthy life,"*[18] whilst a participant living with HIV also noted *"… people closely known to me have been dying all around me. You can't help thinking that you're also in line."*[19]

Comments from focus group participants suggest that, despite HIV prevalence and increasing AIDS-related mortality, disclosure of HIV status is not widespread. This is seen as being influenced by community attitudes, which are related to underlying perceptions of stigma.

> *They keep their children's conditions hidden because they are scared that their families will be associated with the disease.*[20]
>
> *They think that it is a disgrace on the community that a member of a family has HIV.*[21]
>
> *There are situations where you do not even have friends, where if you sit on a neighbour's chair they have to take it outside because you have this thing.* [22]

14 Obanjeni Parents Transcript_O#EB94B doc. Text 3061, 3105
15 Obanjeni Teachers Transcript_T#EB94 doc. Text 136, 296
16 Grahamstown Youth Transcript#14.doc. Text 2725, 2827
17 Vosloorus Clinic Attendees Transcript#28DCB1.doc. Text 2029,2187
18 Grahamstown Youth Transcript#14.doc. Text 10392, 10616
19 Grahamstown PLH Transcript doc. Text 7489-7692
20 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 68515,68897
21 Obanjeni Parents, Transcript#28DCBA.doc. text 4721,4925
22 Grahamstown PLH, Transcript.doc. Text 24911,25145

Knowing one's HIV status may impact negatively. For example, an HIV positive female spoke of encouraging her boyfriend to join her for an HIV test as she suspected that his late girlfriend had died of AIDS. She tested HIV positive and her boyfriend tested HIV negative. This led to her drinking heavily as a product of the belief that *"(her) boyfriend would insult and mistreat (her) because he did not have it [HIV]. He could have easily accused (her) of putting him at risk of infection…"*[23] She was however amazed that he supported her.

Participants also spoke of a positive HIV diagnosis as being a new beginning – "*once a person is diagnosed, then to me it means a new life, it's a new beginning because you then consider that okay I have made this mistake, then I must go back to rectify these mistakes, and change your mind, lifestyle, attitude.*"[24] This construction was linked to AIDS being seen as similar to diseases such as heart disease and diabetes and therefore not exceptional in the sense of being connected to shame and/or blame.

Overall, AIDS was not seen as a manageable disease, and this was linked to the perception of people who had HIV losing weight and dying, with very few examples being known of people who regained their health as a result of being on ARVs.

HIV Prevention

Diverse aspects of HIV prevention were probed during the focus groups, ranging from how individuals give advice to others through to approaches to changing behaviour.

Participants who were parents feared HIV infection of their children:

> *You live in fear, always concerned when your child goes out. When s/he comes back you are worried that something may have happened to him/her. You live in constant fear and wondering how things will be in the following weeks or months.*[25]

In this instance HIV is seen as intertwined with a child's social life. If children '*go out'* now, they may find out that they are HIV positive in the near future. Parents therefore feel the need to protect their children from infection through advice about delaying sexual activity. However, this occurs in conjunction with feeling that the children are not heeding their advice.

The concept of emerging rights for children and youth was felt to be a factor exacerbating risk of young people to HIV infection amongst parents. The relative lack of control over the behaviour of children was seen as contrasting with their own 'strict upbringing' characterized by harsh disciplinary measures and strong moral values, including abstaining from sex. In the current era, children are seen as engaging in risky sexual behaviour, with approaches to strict discipline being curtailed as a product of children's rights.

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23 Grahamstown PLH_Transcript.doc. Text 16186,16484
24 Grahamstown Youth, Transcript#14.doc. Text 3533,3723 & 3726,3774
25 Vosloorus Clinic Attendees, Transcript#EB945.doc. Text 36646, 3617

… now these children have got rights. When you touch [discipline] the child, they say you are abusing the child. A minor touch is seen as an abuse. The child will inform the school; the school will write a letter and advise the child to report the case for you to be arrested. The parent is arrested for doing what he knows to be providing guidance to the child? When you guide the child the government says no, the child should not be disciplined / guided. Children should do as they please because it is their right. Where will these rights take these children? They will end up dead with these rights. They are just floating around with these rights; there is nothing that anchors them because of these rights. We never had these rights; we used to respect our parents.[26]

The other thing that I have observed is that the other cause for our children not to behave themselves is that they have been spoiled by this law saying that they have the right to do as they please.[27]

It was also noted that AIDS information was not sufficiently addressing the needs of older people:

It is difficult to talk about AIDS in our marital talks.[28]

Mobilization is happening in communities but people are not involved properly, especially old people. I think they go to houses where there are young people like high school children. But it does not reach old people, like my grandmother does not understand this. For example she asks me what part of you is painful and I discover that she does not understand this thing exactly.[29]

Social Grants

Support systems, particularly grants, were linked to the perception that were the basis for a incentivising pregnancy or acquisition of HIV. Child support grants to poor mothers[30] were pointed out as problematic:

Personally I think the grants should be done away with because I think they are the reason why we have so many teenage pregnancies, because if you can get pregnant surely you have not been using a condom.[31]

26 Vosloorus Clinic Attendees, Trancript#28DCB1.doc. Text 13432,14221
27 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 11314,11526
28 Obanjeni parents, Transcript#2 8DCBA.doc. Text 8362,8473
29 Grahamstown PLH, Transcript.doc. Text 48257,48654
30 Mothers of children between 0-14 years who earn less than R800-00 ($110) in rural, and less than R1100-00 ($155) in urban areas are entitled to a child support grant.
31 Grahamstown Youth, Transcript#14.doc. Text 56579,56783

> *… the grant money can cause AIDS because people do not protect themselves because they want the money… so sometimes you aim for the child and you contract the virus.*[32]

Similar points were made about disability grants:

> *… the grant for people that are HIV positive… I once heard some ladies speaking – one was going to get a grant and the other says no, sleep with an HIV positive man if you want a grant. It is all said so loosely these days…*[33]

> *On the point you raised earlier about people wanting to access grants for the wrong reason … in my case I went in with my eyes wide open because I was struggling and wanted the grant money.*[34]

Respondents living with HIV acknowledged that there were potential risks associated with the grants, but they felt the money helped them access services that are far from their places of residence and helped them obtain treatment for opportunistic infections that was not available at their local clinics. However, some agreed with other groups that this money was often not used to look after their health directly, but it was used to purchase food and to pay for children's school needs.

Individual Perception of Risk

Mcintyre et al (2004) observe that an individual's belief in his or her personal susceptibility to disease is an important element for addressing disease prevention. Participants in this study acknowledged that HIV was a serious health issue that affects everyone: "*AIDS is a very disturbing disease because it is a disease that targets everyone, every child is vulnerable*"[35] and "*Not one of us is not affected by AIDS*"[36]. It was, however, noted that some did not strongly internalise risks of infection: "*There are some that see this thing happening, but tell themselves that it is far from them 'as long as it has not happened to me'. There are people who can see that something is dangerous, but if it has not affected them it is difficult for them to think that it can face them one day.*" [37]

There was also a perception that PLHA might infect others – an interpretation that potentially contributes to stigmatisation. It also points to the complexity of PLHAs internalising a positive diagnosis and the need to adopt HIV prevention practices. This is linked to the perception among some people that PLHA intentionally spread the disease.

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32 Grahamstown Youth, Transcript#14.doc Text 57122, 57306
33 Grahamstown Youth, Transcript#14.doc Text 56822,57119
34 Grahamstown PLH Transcript.doc. Text 44401,44835
35 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 2844,2961
36 Obanjeni Parents, Transcript#28DCBA.doc. Text 1082,1121
37 Vosloorus Tavern Attendees, Transcript#28DCBE.doc. Text 61613,61904

There are several anecdotal reports of HIV positive people deliberately infecting other people with the disease from all the sites. All FGDs reported having heard and or having knowledge of such phenomenon taking place in their communities.

> *What I observe in the township is like once one knows that they are positive they tell themselves that they have to spread the disease.*[38]
>
> *I was referring to the fact that if two people are sleeping together, the woman can easily infect her partner by cutting herself and putting a drop of blood on his gums.*[39]
>
> *… they say that if you have this disease you tell yourself that I will not die alone. I want to die with many people.*[40]
>
> *Someone may disclose and talk and then knowing that he will spread it so that he does not die alone because he got it in whatever way that he got it So he tells himself that he will spread it as well.*[41]

However, this myth is not necessarily acted upon – as one PLHA observed: *"I would say before I got tested I hated condoms and when I was diagnosed I wanted to spread the disease. But I realized I am doing myself a disservice so that changed me and I started to use condoms."*[42]

Condom Use and Sexual Behaviour

There is a perception that AIDS is a general threat to society, and this is linked to a fear of infection to the extent that *"even if you use condom it does not go away"*[43]. Such fears are articulated in relation to suspicion of the possibilities of deliberate infection by other people, unknowingly having sex with an infected person, and the possibility of condom breakages. Such fears within the context of relationships raise issues of mistrust:

> *When you meet someone, say for example you need to start a relationship with someone who has never tested. There is that thing that when you raise the issue, it comes out as a trust issue. As if you do not trust the person, you see. That is what is happening to us. So you are scared to meet people, you are scared to pursue relationships because you are scared that when you get to raise the AIDS issue it is like you think of yourself as being better or you do not trust the person. That is what is scary, because you will not manage to stay (in the relationship) and not be conscious about it,*

38 Vosloorus tavern Attendees, Transcript#28DCBE .doc.11566,11919
39 Grahamstown Youth, Transcript#14.doc. Text 19138,19373
40 Vosloorus Clinic Attendees, Transcript# 28 DCB1.do. Text 69659,69956)
41 Vosloorus Tavern Attendee, Transcript#28DCBE.doc. Text 6399,6860
42 Grahamstown PLH, Transcript.doc. Text 19005,19217
43 Grahamstown Youth Transcript#14.doc. Text 18754;18946

as it is something that is real. Even though people are so ignorant, they do not want it to be closer to them.[44]

So I can't trust anyone, even if they tell me they do not have it.[45]

There is a general agreement amongst all respondents that HIV prevention through condom use within relationships is a complicated matter and that consistent condom use is very difficult to implement. Participants noted that asking a partner to use a condom was the same as suggesting the partner was unfaithful and untrustworthy.

And when you ask him to use a condom he will scold you and say: 'What are you suspecting me of doing? What wrong have I done?'[46]

He will tell you that you have started sleeping around. He will ask, 'I have lived with you all these years and now all of a sudden you want me to use a condom? Have you started seeing other men?'[47]

It is difficult to ask a man to use a condom even if you know that there are other women in his life.[48]

Both male and female participants agreed that condom use in long term relationships is not feasible. Older males noted that, having grown up not using condoms, they were less inclined to use them with their wives. Females emphasized that the only way they could allow condom use with their partners is if their partner would admit to being unfaithful.

In other words, when he asks you to use a condom he in a way is trying to tell you that he has gone astray. So he is nervous that he may have got some bad things where he was. But the thing is he will never tell you that he slept with someone else.[49]

Rationalising perceptions of trust in conjunction with fear of infection, includes critical assessment of the rationale for having and maintaining sexual relationships:

I always question the wisdom of being in a relationship nowadays because this seems to be a loophole. No matter how hard you try to look after yourself, the minute you let down your guard and get involved, HIV slips in. Then I have doubts about whether to be in a relationship or not.[50]

The above observations show the reality of AIDS in people's sexual lives. This extends to heightened fears of infection, even in the context of condom use, or more

44 Vosloorus Tavern Attendees Transcript#28DBCBE.doc. Text 3707,4412
45 Grahamstown Youth, Transcript#14.doc. Text 29962,30027
46 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 31460,31596
47 Vosloorus Clinic Attendees, Transcript#28 DCB1.doc. Text 31612,31818
48 Obanjeni Parents, Transcript#28DCBA.doc. Text 12395, 12495
49 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 34561,3484
50 Grahamstown Youth, Transcript#14.doc. Text 3224,3511

generally, in relation to having sexual relationships. In this sense, fear is ever present and participants recognise the need to be on one's guard against infection.

Participants put forward a number of myths about condoms:

> *… I asked myself why is it that our children die so much while they are using the condoms. Is it because the condoms themselves cause this disease?*[51]

> *There is this other girl who told me that if you take a condom and put it somewhere in the sun, you will see worms coming out of the condom.* [52]

> *You know some HIV positive persons develop worms on their private parts. Maybe it is these condoms that caused all this.*[53]

Scientific information – for example, rates of condom effectiveness – are not understood clearly, and may also be conflated with incorrect information. This is illustrated in the following comment, where information about condom efficacy (which is scientifically established as approximately 80%)[54] is conflated with the notion that fluids can pass through a condom.

> *Condoms are like seventy-nine percent safe, you understand. They're not a hundred percent, but there's a percentage. … From a documentary I watched on Special Assignment, they said it is seventy-nine percent. … So they poured into it a specimen of semen, ne, and then they pulled on it like that. And then you could see like… because the problem is it's got pores and you could see the semen actually coming out.*[55]

Actual problems with condoms also disincentivise use – for example condom breakages, perceptions of differences between condoms distributed by government and commercial brands, and issues to do with allergies.

> *And besides the pores, there is a risk of it bursting, sometimes you use it and it bursts.*[56]

> *It is a common problem. The same as the lubricant in condoms, some people are allergic to it, like me. If I use it today I develop a rash after a couple of days, so I decided to stop using it altogether.*[57]

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51 Vosloorus Clinic Attendees, Transcript#28DCD1.doc. Text 46002,46166
52 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 45737,45918
53 Vosloorus Clinic Attendees, Transcript#28DCB1. doc. Text 46594,46725
54 Weller, S. & Davis, K. (2002) Condom effectiveness in reducing heterosexual HIV transmission. The Cochrane Database of Systematic Reviews. Issue 1. Art. No. CD003255
55 Grahamstown youth, Transcript#14. Text14582,14640; 1490,15001 & 15059,15388
56 Grahamstown Youth, Transcript#14.doc. Text 15631,15732
57 Grahamstown Youth, Transcript#14.doc. text 16329,16535.

> *People do not like the condoms that the government distributes. Most girls in the community say that the condoms cause rash when they use them with their boyfriends. The sister advised them to stop using them if they cause rash and buy the ones from the garage because these condoms are not the same.*[58]

In the rural community it was noted that condoms were often not available, while other factors also disincentivise access – as one participant noted: *"We do not know who to ask for the condoms and it can be embarrassing as well when we have to ask for them."*[59]

Inconsistent condom use, in conjunction with promiscuity, was noted to be a problem, particularly amongst youth:

> *… what I want to bring home is that people expose themselves to the risk… in spite of the availability of these things (condoms). These things are there, they are always there. But even when you look outside, you get children of fourteen, to eighteen… twelve. These children are pregnant… People do not use it… and even those that use it do not use it regularly – they use protection for three months, [then] they meet another person and in the heat of the moment there is no condom, or they say I have been with this person three months. So I want to say these things cannot be rationalized.*[60]

Promiscuity was seen as linked to unemployment, and the lack of things to do when unemployed:

> *And you see everyday you wake up, clean, you eat, you bathe and sit around. You see, it is better then to go and visit my boyfriend. Soon you meet another one and you visit him as well, you see. So if a person can work, knowing that I am going to work, there is no longer idle time spent in the township, because you have less time and maybe you have things to do. In that way it can end up, you see.*[61]

Alcohol and Drug Abuse

Alcohol and drug abuse came up very strongly as factors that compromised HIV prevention. Alcohol use, and other forms of substance abuse, are linked to diminished rational capacity and have implications for HIV risk (Leggett, 2001).[62] In terms of the findings of this study, respondents who were parents observed that children were involved in "*… drinking and taking drugs… once these people take their alcohol and*

58 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 45230,45451
59 Obanjeni, Parents, Transcript#28DCBA.do. Text. 11412,11585
60 Grahamstown Youth, Transcript#14.doc. Text 25228,26009
61 Vosloorus Tavern Attendees, TranscriptEB94D.doc. Text 58272,56673
62 Leggett T. 2001, Drugs, Sex-Work and HIV in Three South Africa Cities, *Society in Transition*, 32: 101-109.

drugs and smoke dagga, they no longer think of using condoms, they just sleep around, boys and girls alike."[63]

The role of alcohol and drug abuse in diminishing use of condoms was acknowledged by the youth respondents:

> *With me, eish. When I am sitting and drinking, when I see a gorgeous girl, I say to myself, this one I am winning her. Next thing we go to the other. Then you tell her the way you love her and kiss each other. From there condom is not available (or not used). I tell you the truth, you see alcohol misleads you. With alcohol, you forget the condom, even if it is in your pocket.*[64]

> *Yes. You see when I leave here like now, I cannot sleep with a chick without a condom. But the minute I drink strongly, that is where I consider a condom a waste of energy. I hit her fresh.*[65]

> *… They go to clubs and when you are intoxicated a lot of things happen.*[66]

In Vosloorus, parents reported having confronted the local councillor to ask him to close down one particular tavern notorious for attracting young people. It was felt that young people who frequented that tavern engaged in risky sexual behaviour.

Antiretroviral drugs

Treatment of AIDS with antiretroviral drugs (ARVs) is available through public and private health care facilities in South Africa, although it is not yet universally accessible. ARVs were noted to transform the health of people ill with AIDS:

> *Nowadays tablets are there, the ARVs. And as for me, I live with them [PLHA], two of them, a child and a father. I stay with them and I take them to the hospital that is that side for their medication. The pills seem to be working as they are getting better now….*[67]

> *Then he got his treatment. He is still on treatment. I see him getting better and the Lord giving a hand. Now he looks much better.*[68]

However, participants noted challenges in terms of ease of access and ability to adhere to treatment:

> *The Eshowe hospital is [the only one] and caters for a large area and the wards are overcrowded. They make you sit at the benches for a long time if you are bringing in an ill person.*[69]

63 Vosloorus Clinic Attendees, Transcript#28DCB1. doc. Text. 7838,8036
64 Vosloorus Tavern Attendees, Transcript#28DCBE.doc. Text 7604,8012
65 Vosloorus Tavern Attendees, Transcript #28DCBE.doc. Text 8639,8842
66 Grahamstown Youth, Transcript#14.doc. Text 51937,52211
67 Vosloorus Clinic Attendees, Transcript#28DCB1.doc.Text 3087,3378
68 Vosloorus Clinic Attendees, Transcript#28DCB1.do.Text 62439,62609
69 Obanjeni Parents, Transcript#28DCBA.doc. text 10013,10194

They should have clinics on wheels that will be closer to people.[70]

More clinics… that will help in for example, you live in Phumlani and it is a long distance to the clinic, what do you do? It is a long way from Phumlani to the clinic in Joza, so people don't go. So you've already skipped a day, and if it is cold again the next day? Then that is going to have an effect on you.[71]

Participants also noted that access was compounded by a shortage of healthcare personnel – particularly doctors:

First of all a doctor is needed for people with HIV, and not just one doctor for everyone. We need to have our own doctor.[72]

Access to treatment for opportunistic infections is also reported to be affected by irregular supply of medications to clinics and hospitals that are the main AIDS treatment centres in the study communities:

And sometimes you are sick and you go to the clinic and they tell you they do not have medicines… And sometimes you get to the clinic to fetch your treatment and they tell you they are out of stock; that you should buy it yourself.[73]
It is very difficult to get the medication that we need.[74]

Focus group participants also highlighted the fact that ARV treatment has not reached many areas in the country:

We do not know much about these things, but we do hear that the medication is out there somewhere.[75]

The government should make the treatment more widely available to help people. The medication is there, it is just a matter of making it accessible. [76]

To deal with the issue of distance to the treatment centre, an NGO in Grahamstown provides transport for PLHA who are registered with them, whilst another NGO provided access to drugs:

Another useful thing is that they have Medlife and if you do not have money to go to hospital they take you there and back. They can call Medlife to help you at no cost.[77]

Sometimes they help if you run out of treatment or struggle to fetch it from TEMBA, then they let you take it from the centre.[78]

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70 Grahamstown Youth, Transcript#14.doc.48289,48357
71 Grahamstown Youth, Transcript#14.doc. Text 47796,48165
72 Grahamstown PLH, Transcript.doc. Text 34299,34438
73 Grahamstown PLH, Transcript. doc. Text 31921,32278
74 Obanjeni Teachers,Transcript#28 DCB7.doc. Text 5065,5120)
75 Vosloorus Clinic Attendees, Transcript#28 DCB1.doc. Text 38607,38715)
76 Vosloorus Clinic Attendees, Transcript#28 DCB1.doc. Text 38442, 38604
77 Grahamstown PLH, Transcript.doc. Text29628,29813

In the Eastern Cape there is an ARV section at the local clinic which is staffed by HIV positive people who are also on ARV treatment. This was seen as a valuable approach:

> *… at the Masakhane clinic, at the ARV treatment section, the people who work there are on ARV treatment themselves and are HIV positive themselves… So you get served by people who know what they are dealing with.*[79]

Participants noted the importance of good nutrition for PLHA, and that drugs on their own were insufficient for maintaining health. Good nutrition was however, not necessarily affordable:

> *The food should mainly be boiled with water. Even her vegetables have to be boiled, mixed with apples for the person to eat. After that the person can have the tablets. So how is the person going to take medication without eating first?*[80]

> *Another problem in our community is the poverty. People are killed by not getting the right kind of food once they have HIV.*[81]

> *It is difficult because once you know that your child is positive you know that you have to spend a lot of money; not cents. Because when this person is sick, the food gets expensive as you have to cater for their needs as well…*[82]

> *You do not have to drink any juice, you have to drink proper hundred percent juices. So if it is a poor person like me given a medication that is so demanding what will I do? They say the tablets destroy the inside. When you take it, it needs to find something inside that builds your body.*[83]

Other challenges of accessing health care services – such as distance, overcrowding, lack of doctors and waiting lists for treatment – further limit the kind of care that PLHA receive in the study communities. As sick people are unable to access health care in the public health sector, they tend to depend on their family members to provide some care for them:

> *They tell you that if you have meningitis that is caused by AIDS they do not admit such people. Even those who are very ill are treated, not admitted to hospital. And once they see that its AIDS related*

78 Grahamstown PLH, Transcript.doc. text 27394,27529
79 Grahamstown youth, ranscript#14.doc. Text 38146,38571
80 Vosloorus Clinic Attendees, Transcript#28 DCB1.doc. Text 43262,43637)
81 Obanjeni Parents, transcript#28DCBA.doc. Text 5335,5463
82 Vosloorus Clinic Attendees, Transcript#28DCB1.doc.Text43640,44088
83 Vosloorus Clinic Attendees, Transcript#28DBC1.doc. Text 39743,40164

they send them home very quickly … That is when you find ill people locked up at homes alone, if there is no one to take care of them.[84]

Coping amongst PLHA

Respondents and PLHA noted that living with HIV/AIDS sometimes included abuse of alcohol and drugs to try and deal with the psychological impact of HIV infection:

I also smoked marijuana [and] drank, even though I was sick I did not stop smoking dagga and drinking.[85]

When I tested positive in 1998… I told myself that I have what she [the nurse] says I have. Yes, I was naughty and had girlfriends… I started drinking heavily and did not even bother to fetch treatment…[86]

I think I lost a lot of weight because I could not eat the following day if I had been drinking the previous day. So I resorted to drinking… I was also not taking my treatment.[87]

And sometimes you find people drinking because of these sorts of circumstances. They do not have money but another person sees them as lousy and a sorry sight so they decide to cheer them up with alcohol. But their intentions were not to drink but rather they were contemplating a way to get themselves out of the situation they are in.[88]

The need for psychological support for PLHA as a form of care was emphasized by the need expressed for more support groups in the study communities. Participants in all focus groups highlighted the significance of support groups in helping people accept their status towards living positively with HIV as well as in helping affected persons better understand HIV and AIDS. In establishing acceptance of the disease PLHA and others affected, support groups were said to reduce 'felt' stigma and also addressed broader social stigma:

For me what I look for in terms of AIDS, I am scared of the way people treat you the minute you tell them that you have it. People will restrain themselves from you, you see. That is the problem I see in the South, particularly in the townships… But then people are the ones that make some people to be scared of testing, others scared of disclosing about this disease, you see.[89]

84 Obanjeni Parents, Transcript#28DCBA,.doc. Text 9664,9906 & 9910,10009
85 Grahamstown PLH, Transcript.doc. Text 16670,16768
86 Grahamstown PLH, Transcript.doc. Text 20211,2063
87 Grahamstown PLH, Transcript.doc. Text 22462,22732
88 Grahamstown PLH, Transcript.doc. Text 38048,38617
89 Vosloorus Clinic Attendees, Transcript#28DCBE.doc. Text 2466,3025

Support groups were also seen as potential mechanisms for addressing the fear and sense of fatalism, and reluctance to disclose one's HIV status that were perceived as accompanying living with the disease:

> *Some do not even want to hear that they have HIV. It hurts them a lot. That is why they can no longer socialize with other people. They are always thinking about the disease and death. Think about things like taking rattex [rat poison] and stuff.*[90]

> *They do like that [as described above] because there are no support groups that support them to accept their conditions. They do not know what to expect, so they are scared. So if there were meetings where they talked about these things, involving families as well so that when they have an infected family member; this is how you should help him accept his status.*[91]

> *You know when you do not disclose, how are you going to get help?*[92]

Expanded psychological support, beyond the once-off counselling that occur as part of VCT, was also seen as necessary:

> *Not necessarily counselling done in the context of VCT because sometimes when your emotional status is severe then that is not enough.*[93]

> *Yes, like she's open about her status and everything but she says when she goes to bed it still haunts her still… regardless of the fact that she leads a healthy life.*[94]

In some instances it was noted that PLHA were subject to discrimination, but this was problematised as inappropriate and wrong. Fear and discrimination were seen as interconnected – specifically fear of contagion through casual contact.

> *Same thing in the township. My drinking buddies, even though we drink together, you get your friend pulling faces and acting strange when the glass has to come to me because they do not want to drink from the same glass.*[95]

> *Last night I was at a local tavern and I took a five year old child and put her on my lap. It was cold and I had towel around me and I put the towel around the child. She suddenly jumped off my lap and*

90 Vosloorus Clinic Attendees, Transcript#28DCB1.doc.65666,65986
91 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 66076, 66426
92 Vosloorus Clinic Attendees, Transcript#28DCB1.doc.Text 6506,7347
93 Grahamstown Youth, Transcript#14.doc. Text 36791,37286
94 Grahamstown Youth, Transcript#14.doc. text 10139,11010
95 Grahamstown PLH, Transcript#14.doc. Text 45796,46098

told me 'I don't want to sit on you Monica, because you have AIDS.'[96]

And at work it is very difficult because if I get sick my boss threatens to take away my job because I work irregularly because of the sickness. And as a worker, I feel that HIV positive people should be given positions that are suited to our health. The worst thing for me is that sometimes I work in very cold areas even though my boss knows my situation; he simply tells me that he has no other option. I tell him I will get sick and the doctor could have him arrested.[97]

Discussion

HIV/AIDS is a visible and prominent phenomenon in the communities where this study was conducted. Whilst in general, knowledge about HIV/AIDS is high; the disease occupies a range of overlapping and contradictory frames of reference that are strongly influenced by the contexts within which the disease is experienced. AIDS is uniformly associated with death, yet ART is noted as extending life; living with HIV is possible, but people continue to die of AIDS; condoms prevent HIV, but many factors mitigate against correct condom use; HIV is acknowledged as being transmitted through intimate sexual contact, yet there is a persistent fear of transmission of HIV through casual means; living with HIV is linked to bringing shame to families, yet families are supportive and caring of family members who had HIV.

Transmission of HIV is seen as complex to prevent, with HIV being able to 'slip in', the moment a person lets down their guard. Although condoms are acknowledged as providing a means for HIV prevention, they are realistically understood as imperfect for absolute protection against the virus. Further, adherence to a regime of consistent condom use is problematic. Diminished use intersects with feelings of trust as sexual partners get to know each other, whilst alcohol and drug use are identified as diminishing capacity to use a condom – even if a condom is readily available. Asking a partner to use a condom is also associated with a lack of trust, and is unlikely to occur in established relationships where condoms have not initially been used.

Parents were particularly worried about the vulnerability of their children to HIV infection. However, the perception was that children now had rights that mitigated against 'authoritarian' approaches to managing a child's behaviour.

Contextual factors perceived to be influencing the acquisition of HIV were linked to material incentives relating to grants – although this was largely framed as heresay. Amongst PLHA receiving grants, monies tended to be used for expenditures that were not directly health related. Participants living with HIV who knew their status, noted

96 Grahamstown PLH, Transcript.doc. Text 7697, 8045
97 Grahamstown PLH, Transcript.doc. Text 16863,17002

that knowledge of their status was liberating – as an opportunity to take stock of ones life.

The need for psychological support systems beyond the brief support provided by VCT systems was noted. Alcohol and drug abuse were noted to be pitfalls in addressing the process of living with HIV. With regard to care provision, there was a perception that care of PLHA was too readily devolved to family and community members, with health services avoiding their obligations to provide the necessary care.

PERCEPTIONS OF COMMUNITY RESPONSES TO HIV/AIDS

In South Africa, much attention has been paid to top-down, centralised responses to HIV prevention and AIDS mitigation including an extensive condom distribution system, integration of syndromic management for STIs, national roll-out of ARV treatment, interventions such as PMTCT and post-exposure prophylaxis and a number of high-profile national communication campaigns. While undoubtedly important, attention to these high-level initiatives sometimes masks the importance of small-scale community-level initiatives which have been at the forefront of some of the world's most successful responses to HIV and AIDS.

The proliferation of grassroots responses to AIDS has been documented in a number of studies,[98] and can also be through the emergence of a number of HIV-related networks and support structures, in the development of small grants schemes to support the work of CBOs and NGOs, in the large number of organisational entries in the National AIDS Database, and in the large number of CBOs and NGOs receiving funding from government (and private) sources to provide prevention, treatment, care, support and rights services to affected communities and to PLHA.

A growing amount of attention is being paid to how community activity is being organised, how it is being resourced, and what its capacity and support needs may be. Many questions remain, however, about the relevance of such organisations for local residents: to what extent are CBOs, NGOs and other community structures providing support and services that meet people's needs? To what extent is their work known about and valued in the communities in which they are located? How are their efforts perceived?

Previous research in the same communities identified 30 NGOs, FBOs and CBOs in Grahamstown and 24 in Vosloorus which were working in some way on issues related to HIV/AIDS. In Obanjeni, five were identified.[99] In addition to these local efforts, clinics and hospitals are major providers of services and support. These are relatively more accessible in the urban and small town site, as compared to the rural site where a

98 Mwite, Lopes & Dudeni, 2004
99 Birdsall, 2005, p.13

mobile clinic comes once a week and the two nearest hospitals are about forty kilometres away.

This section presents findings on the HIV and AIDS activities being conducted by organisations that exist in the study communities, as well as reflections by focus group participants on the roles that these groups are playing in the community.

Clinics and Hospitals

Hospitals and clinics in the urban areas are located within the vicinity of the study communities and appear to provide a better response to HIV and AIDS related needs than those in the rural areas. Whereas VCT, counselling and support groups were noted to be available in urban Vosloorus, the experience was different in Obanjeni:

> *I know that if you are able to get to Empangeni you can get a clinic.*[100]

> *We need clinics that are going to work even at night and not have to go to Eshowe at night to sit on the benches.* [101]

> *I wish that we did not have to wait for the mobile clinic if we want them.*[102]

However, the issue of distance as an obstacle to accessing public health centres is not limited to the rural community. There are some sections of the urban communities that are located far from the local clinics making access to the public health services cumbersome:

> *It is a long way from Phumlani to the clinic in Joza, so people don't go.*[103]

> *I have seen one person who had sore legs and they had to come from the squatter camp next to Phumlani to get to the clinic. Tell me, if they leave the house at seven, when will they get to the clinic?* [104]

The difference between the urban and rural public health system's response to HIV and AIDS extends beyond physical accessibility to accessibility to HIV related services. A mother from the Vosloorus community related a story of her HIV-positive son who had hidden his condition from her for some time until she realized that he was getting sicker and sicker and decided to take him to the local clinic:

> *I noticed that instead of getting better he was getting worse. I brought him to the clinic. At the clinic they put him on the drip and*

100 Obanjeni Teachers, Transcript#EB94A. doc. Text 4995,5063
101 Obanjeni Parents, Transcript#28DCBA.doc. Text 10312,10425
102 Obanjeni Parents, Transcript#28DCBA.doc Text 11875,11950
103 Grahamstown Youth, Transcript#14doc Text47796,48165
104 Grahamstown Youth, Trancript#14 doc Text 48433,48825

transferred him to the hospital. At the hospital they put him on another drip.[105]

The above situation, whereby an HIV positive person was treated and referred to another health care centre for further examination, contrasts with the one found in the rural public health systems whereby:

Those that are very ill are treated, not admitted to hospital and once they see that it is AIDS related they send them home very quickly.[106]

Participants noted that when people are turned away from the health system, they tended to become isolated: *"that is when you find ill people locked up at homes alone if there is no one to take care of them."*[107]

Urban public health centres also provided HIV education and VCT to community members:

At the clinic they teach us that babies, when they are still in their mothers' wombs, there are diseases that mothers can transmit to them. They tell us that there is help to help protect the child from getting the disease. [108]

They even teach us how to protect ourselves in cases where the husband is likely to bring the disease home. When he comes home I need to sit down with him, negotiate and reach an agreement to use the things to protect ourselves to avoid spreading it more. They teach us a lot of things." [109]

We go to the clinic and test.[110]

HIV education and VCT at the rural site are apparently more elusive:

I am here for more than twelve years and I have not seen any (HIV) awareness programmes here. [111]

We also need to be educated to understand HIV and AIDS. [112]

Do we have people who teach the community about the services available or do HIV awareness? We do not have such services. It is only in the hospital and not in out community. No one teaches the community. [113]

105 Vosloorus Parents, Transcript#EB945.doc. Text 60663,60887
106 Obanjeni Parents, Transcript#EB94B.doc. Text 9910,10009
107 Obanjeni Parents, Transcript#EB94B.doc. Text 10013,10194
108 Vosloorus Clinic Attendees, Transcript#EB945.doc Text 25349,25770
109 Vosloorus Clinic Attendees, Transcript#EB945.doc Text 25928,26244
110 Vosloorus Clinic Attendees, Trancript#28DCB1.doc Text 29994,30035
111 Obanjeni Teachers, Transcript#EB94A.doc. Text 5445,5527
112 Obanjeni Teachers, Transcript#EB94A.doc Text 6805,6861
113 Obanjeni Parents, Transcript#EB94B.doc Text 6801,7018

> *[It is] difficult to deal with AIDS in our area because we do not have counselling.*[114]

One clinic in Vosloorus also accommodates health promoters who are employed by the government to *"distribute condoms and in other places they teach them, they give them condoms. These female condoms I saw them for the first time from these people."* [115] The clinic also shares its space and resources with home based care group members, who *"move from here at the clinic, having addresses of people who need help and visit them in their homes."* [116]

Public health centres in both urban and rural sites are reported to lack human and medical resources to provide quality treatment for HIV positive people: *"They make you sit at the benches for a long time if you are bringing in an ill person"*[117] and *"It is very difficult to get medications that we need."*[118]

Home Based Care

Family members noted: *"We are nurses now,"* [119] whilst one PLHA commented: *"My family supports me"*.[120]

The predominant level of care available for PLHA in the study communities is typically bathing and feeding of the sick person. While family assistance with ARV intake was mentioned in the urban sites, there was no mention of such assistance in the rural site. Even Home Based Care (HBC) group members have very little to offer in terms of therapeutic help when they visit the sick, *"when they get there they find people already sick, they even have very little to do to help at that stage. So they come there like to prepare the person for death"*.[121]

Health seeking behaviour literature notes that persons suffering from diseases and/or families taking care of them during their illness look for alternatives if they cannot access their 'regular' treatment centres. This may extend to consulting traditional healers (*inyangas*). Participant comments included:

> *The inyangas were taught about AIDS but they still keep the people in there until they are very late, before they can go to hospital.*[122]

> *Traditional medicine, if taken with hospital medicine should not be prohibited for patients.*[123]

> *The use of enema (as usually practised by traditional healers) should be avoided in AIDS patients.* [124]

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114 Obanjeni parents, Transcript#28DCBA.doc. text 1372, 1452
115 Vosloorus Tavern Attendees, Transcript#EB94D.doc Text 59288,59349
116 Vosloorus Clinic Attendees, Transcript#EB945.doc Text 58056,58246
117 Obanjeni Parents, Transcript#28DCBA.doc Text 10013,10194
118 Obanjeni Teachers, Transcript#28DCB7.doc Text 5065,5120
119 Vosloorus Clinic Attendees, Transcript#28DCB1.doc. Text 10142,10171
120 Grahamstown PLH, Transcript.doc. Text 24761,24794
121 Vosloorus Tavern Attendees, Transcript#28DCBE.doc.Text 35509,35828.
122 Obanjeni Parents, Transcript#28 DCBA.doc. Text 13011,13208
123 Obanjeni parents, Transcript #28DCBA.doc.Text 13210,13305

There is an overall emphasis on care and support devolving to local communities and a range of individuals and organisations provide support:

> *People from our church do visit those that are sick. Some are bathed as you find that there is no one helping them. Some have their laundry done and cleaning as well as there are no people who look after them at home.*[125]

> *In my ward there is a lady who organized women into an organisation that will visit those who are sick.*[126]

> *I was the only girl at home, it was a must for me to always be with her [HIV positive relative]….Then as I was saying, there were people who used to come and bathe her and stuff.* [127]

The care provided by family members and home-based caregivers also includes encouraging HIV-positive individuals to eat their food and take their medication as well as counselling them to accept their status. The challenges inherent in this role are highlighted in the following statements:

> *Sometimes the person does not even want to be bathed. The person does not even want to take medication. She does not want to eat sometimes. She would say, 'You leave your homes to come here and disturb me. Who told you I am hungry?' You just have to take it all in your stride and make jokes with and help them get better. Sometimes when you bring the medication the person will say: 'You are so dedicated to giving me these tablets. Why are you not taking them yourself?'...You just need to be patient with them until they calm down and do as required.*[128]

> *They want patience. If you press the wrong button you will be in for it. Some do not even want to hear you say they have HIV. It hurts them a lot.*[129]

> *You feel sick as well when you nurse a sick person. I had a sick person in my family. So at times when you are with the person, when you see them feeling the pain, although it was two years ago, we felt sick as well.*[130]

In some instances, caring for PLHA at home is seen as a way of protecting them, and the family as a whole, from the stigma associated with AIDS. Several examples were

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124 Obanjeni Parents, Transcript#28DCBA.doc.Text 13477,1353
125 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 35885,36227
126 Vosloorus Clinic Attendees, Transcript#28 Text 44771,44879
127 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 36254, 36616
128 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 64531,65196
129 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 65666,65986
130 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 3991,4320

given of family members keeping relatives with HIV/AIDS at home and hiding them from the public – to a point of hiding them from potential help:

> *Some parents hide their children from the public once they discover that the child has a disease. 'Oh here comes a visitor, close the door. The visitor should not see the child'. When you ask where the child is you are told that the child is not around, whereas the sickly child is locked in a room in the house. Maybe the visitor would come up with some help, but the parents hide the child from such help.*[131]

> *The other troubling thing is that after visiting and maybe seeing the person,(people) then go around the community talking about how close to death the person is.* [132]

> *(People) go around telling all sorts of people, instead of trying to help the person. That is why people do not want to let people see the sickly.*[133]

In Vosloorus there are two youth organisation's which target out of school young people who are likely to be missed out by HIV education and information provided at schools. The organisations share the same yard, in one section of the community, which limits reach to young people from other sections of the community.

The demand for home-based care (HBC) services has led organisations like Treatment Action Campaign and the Raphael Centre in Grahamstown towards training community members in home-based care for free to meet the demand for the service:

> *TAC took us to St. Johns at no cost to do home-based care and first aid training. We also got the home-based care training from Raphael centre.*[134]

It is acknowledged that whilst home-based care initiatives are helpful, *"the problem is so big that even if you want to help (adequately) you cannot, because there is so much to be done for the basic needs only".*[135] This comment suggests a need for caregivers to receive greater support to meet both basic needs – food, shelter, hygiene – as well as psychological needs that PLHA and their families have.

There are significantly fewer HBC organisations in the rural community than in the other two sites.[136] The lack of financial support is reported to have a negative impact on the local organisations' ability to provide HBC in the rural community:

131 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 67565,68274
132 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 72499,72666
133 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 72669, 72850
134 Grahamstown Youth, Transcript.doc Text 28353,28662
135 Obanjeni Teachers, Transcript#28DCB7.doc Text 2659,2784
136 Birdsall et al, 2005

We have home based care workers, but they are very few. They are not even paid on time.[137]

Are you talking about Siyaphumelela home based care? Yes, I see that people are struggling again. They were going to help the bedridden in their hygienic needs, but it has stopped again now. If you get sick you die on your own.[138]

We have them but they are very few to be having a noticeable contribution in the community. [139]

They have stopped working because they are not getting anything in return. Even the help they get at the hospital is temporary. Those who started the volunteer services were temporary. The problem that they work without being paid reduced the eagerness to do the job.[140]

They did not get the support they needed and even the material they needed to work with. They did not get the remuneration of any form of monetary reward and they had to stop.[141]

The issue of financial support as a hindrance to youth volunteering to the provision of HIV-related services was also raised in urban FGDs:

Nowadays money talks, and then the youth do not want to get involved in things that do not pay.[142]

If they can give me money, I would start with the guys and tell them that guys there is such an amount of money. We need to work this much and in this way in our community. If ever there is someone who gets sick and die without us having seen that person, there will be a problem, we will not get the money.[143]

As the brother have already said, if you can have money and tell them that you have money they will come.[144]

So the main attraction here is money. People will look at how much they put in and how much they earn.[145]

The call by Obanjeni community members for an *"NGO from outside Obanjeni (to) come visit us"*[146] illustrates that the need to look outward for resources and assistance.

137 Obanjeni Parents, Transcript#28DCBA.doc Text 6465,6561
138 Obanjeni Teachers, transcript#28DCB7.doc Text 5832,6066
139 Obanjeni Parents, Transcript#28DCBA.doc Text 6370,6462
140 Obanjeni Parents, Transcript#28DCBA.doc Text 7022,7383
141 Obanjeni Teachers, Transcript#28DCB7.doc Text 5652,5826
142 Grahamstown Youth, Transcript#14.doc Text 62656,62754
143 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 53829,54302
144 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 55520,55659
145 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 55695,55808
146 Obanjeni Teachers, Transcript#28DCB7.doc Text 10436,10484

Material Support

Community members and local organisations also provide nutritional, hygiene and clothing support to the PLHA as well as their families:

> *In my community there is a mother who passed on and left behind three children. She was a hard working woman. Her husband was the first one to pass on, then she followed. Then it was very hurting as we had to do things for her, feed her and bathe her.*[147]

> *What I mean is that sometimes you find a sickly person living alone with small children. When you go to visit her you can see that she has no food. It is better for us who have been given plots to plant spinach because when I go to visit I can pick up some to give her to cook for herself and her family.* [148]

> *Like in the clinics with counsellors, you can be counselled by people other than nurses, then if you have a problem that has to do with nutrition and stuff to eat, then they hook you up with organisations that are around like Masibambisane.*[149]

Local level fund raising was seen as a means to generate resources for material needs.

> *The Department of Health…work with the College of Transfiguration and then they recruit schools. So they work together and recruit schools. They organise concerts and then the schools perform there, they get money from the concerts and donate to HIV-positive children, some are orphans – so they buy them uniforms and supply them with food parcels and all that.*[150]

Orphans and Vulnerable Children (OVC)

As parents die of AIDS-related diseases, they leave behind children – often in the care of their grandparents:

> *You become a new parent again, taking care of his/her children. They become yours.*[151]

> *I am 54 years now. But now we have to start from scratch, and take care of the children.* [152]

In some households, orphaned children are left behind to head households at a very young age. Care of children devolves to older children, with apparently few other options for support:

147 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 4418,4697
148 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 71429,71745
149 Grahamstown Youth, Transcript#14.doc Text 33175,33452
150 Grahamstown Youth, Transcript#14.doc Text 41020,41427
151 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 9599,9713
152 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 9899,9985

Children take care of other kids."[153]

You find that the mothers have died and they are left with extended families or they are living on their own. [154]

Some of the young kids are also taking care of the younger kids in their families. They have enormous family responsibilities and we do not have an orphanage in our area. [155]

Home based care services are provided by individual community members as well as local organisations to deal with the needs of PLHA as well as affected children. As there is a huge need for home care, there is a very real danger of families and individuals who do not have the means or the knowledge, and who have very little access or control of the resource needed to assume this responsibility, being left to their own devices to carry the care giving responsibility and work. Family and local care givers need guidance, support and skills to manage the complex HIV care. Well-supported home care can improve the quality of life of patients of all ages and caregivers alike.

Involvement of PLHA

A number of examples were made of PLHA caring for the sick in the study communities:

You also find that most of the people I have seen like in the community; those that help people, most of them are those that already have this thing, you see. So they tell themselves that they have to help others.[156]

Because most of the time, you will never find a person who knows that s/he is not positive; s/he is alright, helping those people. It is them only. They have sessions that they have to encourage each other and to visit each other and stuff. They do it on their own. They are no community members that are involved in such things.[157]

The concept of support groups is well known in all study communities. The idea of organising meetings where people with HIV/AIDS can get together and discuss their feelings, common problems and ways of coping is valued:

From the onset, even when you have not accepted the disease you get people that sit with you and make you feel accepted and at ease… and get a lot of advice from the older members about what to do and what not to do.[158]

153 Obanjeni Teachers, Transcript#28DCB7.doc Text12564,12715
154 Obanjeni teachers, Transcript#28DCB7.doc Text 2458,2567
155 Obanjeni Teachers, Transcript#28DCB7.doc Text 1836,2013
156 Vosloorus tavern Attendees, Transcript#28DCBE.doc.Text12346,12559
157 Vosloorus Tavern Attendees, Transcript#28DCBE.doc. Text 32801,33199
158 Grahamstown PLH, Transcript.doc Text 28861,29147

Support groups are *"like a school about HIV"*[159] and they help people *"to know how to live their lives after they have been diagnosed with HIV."*[160]

Although the concept is familiar in all study communities, support groups do not necessarily have the same coverage in all three sites. Whilst several support groups exist within the vicinity of the urban study communities, these are not perceived to exist in the rural community: *"I have not heard of any so far. I have not heard of support groups."*[161] Additionally, organising around AIDS may be misperceived: Facilitator: *"What are the problems to having support groups in your community?* Respondent: *"Lack of unity in our community. People will think you want to talk about politics."*[162]

In communities where they exist, some support groups provide micro-economic skills training to members:

> *Yes, she works with them and she teaches them things like music and a whole lot of other things.* [163]
>
> *They had sewing projects when I last checked. Sewing and handiwork.* [164]
>
> *The gardens are there even at Joza clinic, there is a garden with spinach.*[165]
>
> *Raphael centre is a centre for people that are HIV positive. They spend the day there and are also provided with meals. There is also training/education going on there like gardening, sewing and cooking classes. There is also counselling and music.*[166]
>
> *There are also courses, because I also have a certificate for gardening and cooking from there.*[167]
>
> *We sing and practice singing and do stage plays. Like now we are going to have a concert so we are practicing now.*[168]

Membership to one particular support group in Grahamstown, located at Jabez Centre, provides members and their immediate families with transport to the hospital when they are sick, thereby making access to health services much easier:

> *You have to pay R40 for the service, like me and my family every month. So anyone that is sick in the family is taken to hospital and*

159 Vosloorus Tavern attendees, Transcript#28DCBE.doc Text 32505,32582
160 Obanjeni Parents, Transcript#28DCBA.doc Text 10850,10936
161 Obanjeni Teachers, Transcript#28DCB7.doc Text 4544,4792
162 Obanjeni Parents, Trnacsript#28DCBA.doc Text 12194,12349
163 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 35402,35690
164 Grahamstown Youth, Transcript#14.doc Text 36289,365500
165 Grahamstown Youth, Transcript#14.doc Text 60899,60979
166 Grahamstown PLH, Transcript.doc Text 26961,27303
167 Grahamstown PLH, Transcript.doc Text 30131,30325
168 Grahamstown PLH, Transcript.doc Text 30413,30617

back. So if you are a member, your family is covered through your membership at the centre.[169]

Faith Based Organizations (FBOs)

All FBOs referred to in this study are Christian in orientation. The main HIV and AIDS related service offered by these organizations is spiritual support to both PLHA and their family members:

In my church we help them with prayers. I mean those who have HIV. We pray for the Lord to help them.[170]

The praying families cope better with AIDS in the family as they get hope from praying and get strength to carry on with their lives."[171]

It is easy to cope with it if you are a church going family. We get together, cope and share the burden.[172]

The churches also provide HIV and AIDS education and were seen as important sources of information in the rural community.

I invite the children to church. I reckon that as we are a large women's group in church, we are able to guide our children. Because now it is useless to cry about HIV. It is here and it is real. Life should go on. We should try and find ways as to where to from here. So we try to invite these children to church on Sundays, although it is tough we try.[173]

We do not have organisations, but the churches are helping by providing moral support, teaching about HIV and AIDS to the communities.[174]

Stigmatising attitudes may however prevail in the context of church attendance:

I have a cousin who is HIV positive… even at church no one sat next to her… she had to organise workshops to educate the church people.[175]

Even if there is a positive person who discloses, they do not teach about those things in my church.[176]

Some churches do not want to accept your obituary if you write the cause of death. They tell you they do not work like that. Then you have to look for a new church simply because you want to be open

169 Grahamstown PLH, Transcript.doc Text 35933,36322
170 Vosloorus Clinic Attendees, Transcript#28DCB1.doc .35885,36227
171 Obanjeni Parents, Transcript#28DCBA.doc Text 1710,1845
172 Obanjeni Parents, transcript#28DCBA.doc Text 2242,2344
173 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 24348, 24823
174 Obanjeni Parents, Transcript#28DCBA.doc Text 7826,7957
175 Grahamstown Youth, Transcript#14.doc Text 11340,11934
176 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text34443,34555

> *about the fact that you died of AIDS. This happened to my sister and she ended up not being buried by her church, but was buried by Zion church.*
> *Facilitator: What was the church's problem? Respondent: That she wanted it to be said that she dies of AIDS.*[177]

In the rural community, condom distribution was also seen as potentially possible via the church: *"They can place them at the church"*[178]

Taverns

Tavern attendees report that taverns are involved in HIV prevention efforts through making condoms accessible to the patrons. Tavern owners, particularly in the Vosloorus community, are reported to put condoms in both public areas like the counter and private places like the toilets for drinkers and lovers to pick as the need arises: *"They put condoms in their boxes. They know that when we are drunk we need them".*[179]

Some participants reported that the tavern environment is conducive for communication around sensitive matters such as sex and HIV:

> *You know how easy it is? It is very easy! Very, very easy. Like the issue of talking, it is easy to talk. It is easy to discuss when there is alcohol. You know where there is alcohol, there are right people.*[180]

In taverns, *"the sex topic is always on the table"*[181], providing an opportunity for HIV and AIDS- related discussions as well. This is supported by the report that tavern owners and patrons alike feel free, within this environment, to advise fellow patrons to pick up condoms once they see them getting cosy with the opposite sex:

> *Some even remind you when they see you. When they see that you have caught someone. When you go to the counter and buy alcohol, they will tell you: 'Do not forget these things.'*[182]

The idea of having taverns as active HIV and AIDS education centres was also raised in the Grahamstown FGD:

> *I also feel that even at the taverns there should be things like video cassettes that show people the dangers of HIV/AIDS. Right in the places they gather in.*[183]

Alcohol is noted however, to skew rationality:

177 Grahamstown PLH, Transcript.doc Text 52602,53078
178 Obanjeni Teachers, Transcript#28DCB7.doc. text 11368,111455
179 Vosloorus Tavern Attendees, Transcripts:#28DCBE.doc Texts 21983,22026&22046,22103
180 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 21644,21868
181 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 22753,22804
182 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 22176,22383
183 Grahamstown PLH, Transcript.doc Text 50145,50311

Yes, you can agree when you are sitting together as a group. But when he gets there [he thinks to himself], 'The friend is mad, he also has plain sex [no condom]. Then he goes straight [has sex without condom].'[184]

Once these people drink…they no longer think of using condoms, they just sleep around.[185]

PLHA

PLHA are reported to be active in addressing HIV/AIDS, although some impacts are also related to a 'passive' effect produced by fear of being ill as exemplified by people who are severely ill from the disease.

It is like sometimes when you see what is happening on TV, you think that you will experience the same thing and get to that stage; that is where the fear takes over.[186]

People that do not want to use condoms (should) be shown what it is in the end. Like the photos that are at Joza clinic; there are photos there that are gruesome to look at and you imagine if that were you, how it would be like.[187]

Active involvement of PLHA in the provision of HIV and AIDS-related services ranges from actively educating people about the disease to being involved in the care of those already living with HIV:

… like that guy we went to see in Joza, ja he's positive and he does not hide it… He just speaks about it frankly and is always ready with advice for anyone.[188]

The HIV positive persons… are visiting other infected persons.[189]

There are summits, all of them are HIV-positive and they fight to protect the rights of others that are HIV positive.[190]

At the Masakhane clinic, at the ARV treatment section, the people who work there are on ARV treatment and are HIV positive themselves. The people you deal with there are on ARV treatment and are HIV positive themselves. So you get served by people who know what they are dealing with. [191]

184 Vosloorus Tavern Attendees, Transcript#28DCBE.doc Text 23985, 24177
185 Vosloorus Clinic Attendees, Transcript#28DCB1.doc Text 7838,8036
186 Grahamstown PLH, Transcript.doc Text 4734,4912
187 Grahamstown Youth, Transcript#14.doc Text 51228,51546
188 Grahamstown Youth, Transcript#14.doc Text 33534,33938
189 Vosloorus tavern Attendees, Transcript#28DCBE.doc Text 33887,34104
190 Grahamstown Youth, Transcript#14.doc Text 37319,37556
191 Grahamstown Youth, Trancript#14.doc Text 38425,38571

> *On the issue of these people that are specifically for HIV/AIDS are people who access that service saying that helps in the sense that there is no longer scolding and rudeness, here is someone that knows and understands the needs of someone who has AIDS. It helps because when they get there they feel comfortable talking to the person and communicate freely to the person.*[192]

PLHA also provide referral to services, and open disclosure provides a connection point for other's living with, or affected by, HIV.

> *There are also other people who are HIV positive you can go to and then they can hook you up with other organisations.*[193]

> *Then they tell me, 'I'm sorry to bother you but my child has that thing of yours.'*[194]

In Grahamstown, respondents mentioned the work of the Treatment Action Campaign (TAC) and the National Association of People Living with AIDS (NAPWA). The TAC was reported to "*fight for the right to treatment, whatever it may be. That it is administered in the right manner and everyone that should get it actually gets it.*"[195]

Discussion

HIV/AIDS is clearly being addressed openly in all the study communities. The disease, and discourses about the disease, are present in family space, workplaces, schools, churches, and taverns.

Systemic response occurs in clinics and hospitals, but also in the existence and emergence of wide ranging non governmental and community level organisations, and also individuals. The rural site, Obanjeni, is however distinctly disadvantaged, with no formal health facilities, and very little in the way of community-level support. Travel is thus an immediate problem for those needing healthcare.

There were reports of varying efficiencies within the health services including people with HIV/AIDS being turned away and variable levels of avaibility of ARVs. However, clinics were playing a role in providing education and services such as VCT.

Home-based care services were provided by various groups including faith-based organisations and PLHA. HBC provision included training, provision of resources and psychological support, with resources being secured through direct funds as well as fundraising activities. Lack of access to ARVs was noted.

192 Grahamstown Youth, Transcript#14.doc. Text 49893,50287
193 Grahamstown Youth, Transcript#14.doc Text 32938,33079
194 Grahamstown PLH, Transcript.doc Text 9697,9778
195 Grahamstown PLH, Transcript.doc.Text 25601,25820

In some instances, families were ashamed of family members who were ill with AIDS, to the extent that these individuals were ‘hidden’ from the community.

Orphaning was a common problem, with the burden often falling to grandparents or older orphaned children.

Various forms of support were provided by organisations generally, with those involved ranging from formal employees, to volunteers and also to PLHA. PLHA predominate in support groups.

FBOs were directly involved in spiritual support provision as well as addressing educational and material needs. Taverns were active in provision of condoms.

CONCLUSIONS

HIV/AIDS is recognised as present in all study communities, and there does not appear to be a strong stigmatising association with the disease – although stigma is by no means absent.

Overall levels of knowledge are high, and it is acknowledged that in spite of good knowledge, HIV is difficult to prevent. Limited efficacy in HIV prevention is related to intersections with difficulties in ensuring consistency of condom use, influence of alcohol, limited authority of parents over children, and perverse incentives such as grant monies.

The need for psychological support systems for PLHA was noted.

Community response to HIV/AIDS is increasing, and formal health services are noted to offer varied levels of efficiency of support, and also limited resources. There was a stark lack of resources in the rural site, and most organised community response to the disease appeared to be constrained by limited funding, limited reach, and difficulties in sustaining volunteer staff.

The findings suggest the importance of resourcing and funding community level responses to HIV/AIDS .

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