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MEN AND ARVS:

HOW DOES BEING A MAN AFFECT ACCESS TO ANTIRETROVIRAL THERAPY IN SOUTH AFRICA?

AN INVESTIGATION AMONG XHOSA-SPEAKING MEN IN KHAYELITSHA

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Men and ARVs: How does being a Man affect Access to Antiretroviral Therapy in South Africa? An Investigation among Xhosa-Speaking Men in Khayelitsha

Abstract

This paper aims to improve understanding of the nature and causes of barriers to accessing ARV treatment that affect men and result in their low rates of clinic attendance. The findings are intended to provide a direction for policy in the implementation of the South African government's Comprehensive Plan for HIV/AIDS. Through a combination of semi-structured interviews and focus groups, experiences and opinions were collected from men living with HIV/AIDS and health workers working at an ARV treatment clinic in Khayelitsha, South Africa. Using an interpretivist approach, and informed by theories of social constructionism, an understanding was formed taking into consideration the complex nature of their realities. Thematic content analysis was selected as the best way of handling a large volume of material spanning a broad range of issues. Only by attempting to understand the nature of Xhosa culture and what it means to be a Xhosa man, was it possible to comprehend the material. Barriers to access manifested themselves at several levels of experience. Stigma, gender issues, preference of traditional medicine, cultural ideals of manhood, and several practical issues, all influenced a man's ability to acknowledge his HIV status or to seek help. Suggestions to address these problems were made throughout the paper, founded on a combination of interviewees' opinions and researcher's analysis. These suggestions are important to acknowledge before a national ARV programme becomes fully implementational.

Background

The backdrop to this research is the South African HIV/AIDS situation that continues to approach pandemic proportions. Calls for a comprehensive and freely available treatment programme have long gone unanswered, despite large-scale grass roots activism that even included a civil disobedience campaign (Majola *et al.* 2003). In October 2003, the government of South Africa finally heeded the calls and announced a Comprehensive Plan for HIV/AIDS, with the central pillar being a free, national antiretroviral (ARV) treatment programme (Department of Health 2003). The announcement has been cautiously welcomed by treatment activists (Majola *et al.* 2003), who point to a history of failure to put health, and notably HIV/AIDS policy, into action, within a weak public health system (Schneider and Stein 2001).

Despite these reservations, there is some cause for optimism, especially if one considers the successes of ARV pilot programmes around the world that have operated in a variety of resource-limited settings and have developed a variety of strategies to overcome the array of obstacles to success (Farmer *et al.* 2001; Ahouanto 2002). One worthy of mention, is a Medecins Sans Frontieres (MSF) programme operating from three treatment sites in Khayelitsha, a large peri-urban, African, Xhosa-speaking township outside Cape Town, with an estimated population of 1.5 million inhabitants, and an HIV prevalence rate of 24.7% (MSF 2003).

Since May 2001, MSF have been providing comprehensive treatment for HIV infected individuals in Khayelitsha, distributing generic ARV medication, independently procured using a section 21 authorisation of the Medicines Control Council (MCC) (MSF 2003). On April 29th 2004, clinics admitted their 1000th patient onto ARVs and a target has been set of 1700 by the end of 2004 (Kaap 2004). It is clear that with this unique wealth of knowledge and practical experience within a South African context, any national programme would benefit from the lessons of Khayelitsha. In fact, the programme is well represented in the provincial HIV task team, responsible for the Western Cape's part in the future national programme, and the eventual absorption of the Khayelitsha programme (MSF 2003).

If a national programme is to be a success, not only does the policy have to be successfully implemented, but also the service offered must be accessible to all who can benefit from it (Department of Health 2003). However, one of the more striking findings to come from the Khayelitsha experience, is that the service seems to be far more accessible to women than men. A March 2004 paper showed only 29.9% of ARV patients at the MSF clinic are men (Coetzee and Nattrass 2004), a reality confirmed by clinic staff.

The authors of the Operational Plan call for qualitative research pertaining to the Health Department's AIDS plan in order to "*illuminate circumstances*", and to "*improve the effectiveness of the interventions*" (Department of Health 2003). These factors have informed the aims of this paper.

The literature relevant to this research regarding masculinity tends to fall into two categories. First, is a body of work that discusses health promotion interventions directed at men (Sivaraman 1999; Sternberg 2000). Interventions, for example, to reduce HIV transmission are documented. The second set of research relates to men and help-seeking behaviour (Addis and Mahalik 2003; Moller-Leimkuhler 2002). These papers tend to approach the topics from a psychology perspective and are related to psychological illnesses such as depression. This literature was indeed interesting and instructive, and necessary reading before undertaking my own research. However, there was a paucity of literature that documented men's attitudes and experiences of sickness and how that manifests in behaviour. This niche also served to inform my research direction.

Aims and Objectives

The aims of the paper are to:

- Examine the realities of ARV treatment programmes from the perspectives of men living with HIV/AIDS in Khayelitsha.
- Explore perceived barriers to accessing antiretroviral therapy and the reasons behind these.
- Provide direction for policy that will improve the "efficacy and effectiveness" of the Operational Plan (Department of Health 2003) through elucidating barriers to access from men and health workers.

The objectives of the paper are (through conducting focus groups and interviews with HIV positive men and clinic staff, involved in ARV provision) to understand:

- Some of the reasons why men feel unable to access treatment.
- Some of the difficulties in providing treatment.
- Ways in which a national ARV plan can be made accessible to men.

Methods

This research was undertaken during May to June 2004. Hosted by the University of Cape Town (UCT) (South Africa), Centre for Social Science Research (CSSR), I was able to plan and implement my fieldwork. Ethical approval was obtained from the Nuffield Institute, Leeds (UK) and from UCT's ethics committee.

Fieldwork consisted of one focus group discussion with five men, three semi-structured, individual interviews with men and four semi-structured interviews with health workers at Site B MSF clinic, Khayelitsha. One interview and the focus group were organised through a Treatment Action Campaign activist, a contact from UCT. By arrangement with MSF, I was able to visit the Site B clinic on several occasions and conduct the remaining interviews. A constant comparative approach allowed a feedback process from one interview to the next that allowed pursuit of areas of interest previously not considered.

Methodology and Terms of Reference

An interpretivist approach was taken to this research acknowledging the significance of individual experiences of HIV and thoughts on ARVs. Rather than arrive with preconceived models, drawing on principles of grounded theory, the aim was to allow a collection of experiences to construct a picture of 'basic social processes' (Denzin and Lincoln 2000). Several discussions with researchers and stakeholders prior to my fieldwork had alerted me to the possibility of a strong influence of Xhosa cultural factors[1]. As such, a social constructionist approach to analysis would facilitate an understanding of the complexity of multiple interpretations of cultural identity.

The men that I spoke with were neither representative of the adult, male, HIV positive population of Khayelitsha, nor were they intended to be. They were identified through a Treatment Action Campaign (TAC) activist, or were approached in an HIV/AIDS clinic, and therefore knew their HIV status and were comfortable disclosing this fact and discussing the issues surrounding their condition. (Written consent was obtained in all cases confirming this fact). These men represent a minority in Khayelitsha. However, they are a very important group, for all HIV/AIDS stakeholders hope that this will be a fast-growing minority.

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[1] The region around the Eastern Cape is the traditional home of the Xhosa people, but over the last century many have migrated to the Western Cape to seek employment. Many now live in townships such as Khayelitsha. Cultural values and beliefs are still strongly held. (see People Profile: International Mission Board: www.imb.org/southern-africa/peoplegroups/xhosa.htm accessed 21st July 2004)

The interviews were tape recorded and ranged in length from 30 to 80 minutes. The researcher later transcribed them verbatim. Transcripts were analysed using a multi-stage interpretive thematic analysis, involving several detailed readings of the transcripts in order to generate themes. Following an interpretivist approach, it was decided that only men's transcripts would be used to generate themes rather than use those occurring from health workers. This was an attempt to guard against the effect of outside influences.

Findings and Analysis

The interviewee's perceptions emerged in a haphazard and sometimes contradictory way during the discussions. This section is an attempt to impose order and clarity on the discussions that took place. The following subheadings are not rigid, and indeed some comments fall under several themes, but are felt to be the best way to present the complexity and sheer volume of data.

Due to limitations on the size of this paper, I am unable to examine each point in equal depth. It is hoped that a satisfactory compromise has been reached between breadth of issues and depth of analysis.

Participant's identities have been concealed for reasons of confidentiality. Each participant has been assigned an identifying code. The letter 'H' denotes a health worker speaking and an 'M' denotes a male, HIV positive participant. Numbers range from H1 to H5 and M1 to M8.

Stigma as a Barrier

Stigma and fear of stigmatisation have long been recognised as barriers to the success of a range of HIV interventions (Stein 2003). Despite awareness campaigns and health education in schools, a fear of stigmatisation still inhibits many people from disclosing their status. This situation was reflected in a focus group transference task, whereby participants collectively created a fictional male, typical of their peer-group and discussed behavioural options at points along his story of HIV infection:

> M4: …he didn't tell his family, because he knows they are going to throw him away. From the house.

It is not only family estrangement, but also shame within the community that is to be feared:

> M1: These days there is a lot of pointing fingers. Most of the people who are pointing fingers are the ones who have got positive children in their own houses. They have got positive children. If they know about your status, they will point and say, "That one is positive!" They will make a mockery of it, you see. They do that, a lot of pointing of fingers. But you will find out, if you do a search, that there is someone in their house who has got HIV. And they know, but they want to cover themselves, you see. So a lot of people become scared of coming out, you see? Of going to the test.

Once it became apparent that stigma and fear featured very highly among opinions as to why men refused to admit their status or even assent to testing, I was eager to explore whether participants thought stigma affected men more than women.

A female counselor gave her opinion:

> H4: They affect men more than the women. Women have got no problem. It's the men, what they are thinking is the family, you understand? What my family is going to say. How am I going to live with friends? Understand? Then it's whereby they decide that Ok, I won't come to the clinic…

This was supported by a male interviewee:

> M8: I think it's my experience is that the women in South Africa are open about their status and the men are not open about their status, they are also afraid of the stigma.

Several suggestions were made as to why this fear of stigma accompanying the disclosure of one's HIV status and attendance of clinics affected men more than women.

> H1: …maybe it is more difficult to disclose in a working environment…

> H2: I think the cultural image of men is an image of physical strength that is extremely (.) and this physical strength and potency is very important, so, em, they will feel more ashamed of being sick than women…

> M8: The problem is like this: We go together to the test, so guys tested positive and the girl tested negative, …when we are fighting,

> she is going to shout rudely telling each and every neighbor around her that, "You see this fuckin' nonsense is HIV positive, that is why he is so rude!"

One exceptional participant however, rejected stigma outright:

> M6: But as long as you know yourself, what you are struggling for…having to fear for someone… I dunno, you are just giving yourself a tough time.

Nevertheless, health workers attributed some blame for low male attendance on the stigma surrounding clinic attendance. Whereas patients would be willing to go to a non-specific infectious disease clinic in the main health centre for HIV care, when it came to attending the MSF clinic for ARV treatment, they are unwilling:

> H1: …because they know that this is a separate clinic and people will know that if they come here they are HIV positive, they don't want to come here, even if it means they are going to get treatment here.

To combat male stigma, one man suggested:

> M1: …if we can organize another opening at the back [of the clinic] for men only, you see, they would go, they would go! Because they don't like to be known, that man is going to the HIV clinic. Men like to…have a nice time [all laugh].

A call of optimism came from a male doctor at the clinic:

> H2: …but I think stigma is a… stigma is not here to stay. …in the beginning here, they were very afraid to open an HIV clinic because nobody will come- it's packed. And the more HIV clinics…the less stigma we will have.

Culture as a Barrier

The men and the Xhosa health workers (H3 and H4) referred often to 'our culture'. It appeared a well-defined system of expectations and norms.

> M7: It's our culture, it's our men's culture. Men doesn't allow everything, men allow the women… It is our culture, the Xhosa people's culture.

When talking about the male culture, participants referred to the roles and responsibilities of a man and the characteristics, which were important. The responsibilities inherent in manhood are taught as a man comes of age during rituals such as circumcision:

> M6: Taken to the bush. To be circumcised, you see? Actually I don’t know why…how to put it in…but I will put it in your words, it is the circumcision, you see. But in my word: *Uqualuka.*
>
> Yah, so… the thing is, you reach that stage …of a manhood. Then there is the responsibility that, okay, you are having, because you are being told, you see? When you are coming from bush, you are being told, giving more lectures about manhood, what it…how you are going to behave and all that things. And, you see, to have a wife, go to work, all that stuff, you see, [hushed tones] food, you must look after your family, and aaaaalllll that type of things, you see.

The pressure to conform to these roles may well impact on a man’s decision not to attend a clinic:

> H1: Just a general perception of a man’s role, and his role in the home, that he is very much the bread winner and the strength of the household, I think for anyone to admit that they are unwell in that situation is very difficult…culturally, its less acceptable for men to ask for help, or to admit that there is a problem… the man really is respected as the leader, with the strength, and…yah, very difficult to admit that they might not be able to look after the family, that they might have to stop working…

A Xhosa counselor at the MSF clinic suggested that only a person in a position of authority can compel a man to face his problem:

> H4: Up until there is someone, maybe who is stronger, whether it is the father of the man, who can understand this sickness and he will tell him that, ‘you are sick, you are HIV positive, go to the clinic’, you understand? …It has to be a father, or someone who is on top of him, you understand?

This view is reinforced in the recounting of one man’s discovery of his positive diagnosis: ‘My father forced me to take me into that hospital, he took me by force and we go into Gauteng where I was admitted in Suquwane Hospital.’(M4).

As the older generations are often uneducated about HIV and also place greater faith in traditional medicines than a younger generation, it is often unrealistic to rely on parental pressure as a means of increasing male clinic attendance.

Archetypal Male Characteristics and Beliefs as a Barrier

Characteristics of a Xhosa man were also talked about, usually during an answer to an unrelated question:

> H4: Its because they are stubborn. The men they are very stubborn. They think they are cleverer than anyone.
>
> H3: Um… so it means you are not strong enough as a man
>
> H3: African men they think, we can take charge of our own health…
>
> M6: You mustn't be… a coward, you have to be strong…

Men's reluctance to discuss their problem often appears to manifest itself as stubbornness.

> H3: Sometimes even if you [have] a pain as a man, it takes time to tell even your girlfriend, or partner [laugh] that I have got this pain, but when the pain gets stronger, only then, when you can't take it any more, and then you divulge the information and say ok…They believe that men should be strong to take the pain.

Interviewees referred to not only a stubbornness to accept their diagnosis: 'They deny. Like to deny that, ok, you said that I have HIV, but what I believe, I don't have HIV, they are talking like that'(H4), but also a stubbornness to seek help, even once they realise they might have HIV:

> H3: The stories that we get here, the man says to the woman, no ok, if you are HIV positive it means I am HIV positive, so I don't need to go and test, I'm ok, I don't want to, I don't want anything to do with it.
>
> M1: Most of the time they don't even want to see the name AIDS, he doesn't want to see people talking about it. He doesn't want to see it on TV [M4: Ya], when he see that name he looks away, doesn't want even to see this things. He is scared.

This opinion was supported during a visit to an HIV clinic at Groote Schuur hospital in Cape Town by a lady's account of her husband, as told to her doctor. The lady complained bitterly about her husband's persistent reluctance to accompany her to her clinic appointments. She described his symptoms of sexually transmitted infections and his severe weight loss, but still he shouts, "I don't want to know… it's your problem, not mine." The lady comments to the doctor that she will divorce him and move in with her sister, "I don't care, he can die, then I will just have to look after me."

One comment by a man indicated that rather than the stubbornness being a passive, unconscious defensive tactic, it is instead, sometimes a calculated decision. It is interesting to note that three times in the comment he says 'most men', a clear attempt to distance himself from the actions of others:

> M1: See, most men… see, if my wife is positive, or my girlfriend is positive, I pretend that there is nothing…I tell her she must go to the HIV [clinic], its what they do, most men, they say you must go away to the HIV [clinic], I am not HIV positive. I am fine, I have gone for a test, but I didn't go for a test, [I] am lying, you see. I will go and find another girlfriend, and I will dump that one. Find another one, it's what the men do, most men, cause they don't want to know about their HIV status. Most men.

Failure as a Man

Prescriptions for how a man must live and act may work well for some men, if not the women of the society that are often subjugated as a result of the dominant male culture (Soskolne *et al.* 2003). However, for men who are sick, these expectations can become a burden.

> M6: Happen that, after all those occasions, that you are sitting with your wife, with the children, getting sick. How are you going to achieve all these er, things that you are… in fact needs that you want? You see. Now I am the man in the house, and I am sick and my wife is sick. And those people that they taught me all these type of things, you see, but they never said anything about the sickness.

If a man becomes sick, not only does he feel a sense of failure to fulfill his manly duties, but he also fears rejection from his society for failing to embody suitable characteristics.

> H2: I think the cultural image of men is an image of physical strength that is extremely… , and this physical strength and potency is very important, so, em, they will feel more ashamed of being sick than women so there is perhaps an increased stigma.

No element of the culture stands in isolation. Faith in traditional medicine is widespread and has special ramifications for a Xhosa man:

> H3: I mean that you now, you…have got a disease and that you can't handle it on your own, like a … so traditional medicine has failed you, so you have to go for this western medicine. [Interviewer: And that means you are weaker?] In a way. …[later in the conversation] Um… so it means you are not strong enough as a man.

Throughout the course of my discussions with men, only one man consciously acknowledged the pressure and expectations placed on him as a man:

> M6: Ok, let me put it this way: Being a man in my tradition, it…it cost too much. It cost too much.

What emerges is a picture of a Xhosa man that is both bound by expectations of responsibility, and raised on beliefs that resist help-seeking. This construct, if left unchallenged and intact, is irreconcilable with sickness and asking for help. If men are to attend ARV treatment clinics in the future, a more positive identity must be nurtured.

The man just quoted was unusual in that he realised the constraints of his culture. This is not to say that the other men appeared unaffected by their predicament of being HIV positive within a culture that is unaccommodating of behaviour at odds with the norm; rather, that the others appeared to have processed the situation in a relatively less insightful way.

Traditional Medicine as a Barrier

> 'You can't change somebody's beliefs. It's very inconvenient to change somebody's beliefs.' (M2)

Traditional beliefs, for reasons unknown, appear to be stronger among men than women in the Xhosa culture. As one Xhosa health worker observed, 'I am sure I cannot say why, but women, they are more associated with the western style' (H3). Several health workers suggested that, through birth control, pregnancy and motherhood, a woman is frequently exposed to western medicine and learns to place trust in it, but men are not necessarily exposed at any of these points, and hence traditional beliefs remain unchallenged.

It is not hard to conceive of a situation amongst the township dwellers of the Western Cape, where conflict and confusion arises through the meeting of tradition and modernity. Within a twenty-kilometre radius lie two extremes. Cape Town itself is comparable in development and technology to any western city, yet around the outskirts of this city lie dense swathes of corrugated iron and wooden shacks, most with no running water or official electricity supply. The benefits of modernity are often out of reach due to financial constraints, and given the ugly spectre of Apartheid only a decade in the past, a mistrust of all that is western, and a comfort in the traditional practices of ancestors is often evident. Nevertheless, a desire to be seen as worldly is also visible, even if this is at the expense of traditions. Understanding this context is crucial to interpreting much of the sentiments expressed on the sensitive issues of traditional beliefs and faith in traditional healers. Contradictions even within one person's account hinted at internal confusion.

Some of the men felt that belief in the Sangoma, the traditional healer of the Xhosa culture, was universal among men and the beliefs were passed down from father to son:

> M7: 'I believe in the tradition, in the Sangoma. Few men believe in the drugs, in the treatment, but all men believe in the Sangoma, because our fathers believed in the Sangomas.'

Other men thought that belief in the Sangoma was associated more with rural culture:

> M3: In most cases, it is only those people in the rural areas, like in Eastern Cape, because, there is no information, enough information in rural areas, you see?

Some comments illuminated understanding of HIV/AIDS transmission and illness through traditional beliefs:

> M1: Most people, …they think that HIV thing, because its so, so (.) spreading… so most of them say, no, it's er, witchcraft. They give you injection, like when you are asleep… [laughs], you know, when you are…having sex with a beautiful girl in your dreams, that's the way they get into you, they say so. They say that thing happens…the witch doctors comes to you and they give you a girl and [clicks his fingers] with HIV positive, and you have sex with her, and she gives you HIV.

> M8: …one thing most of the guys say, is it is Satanism, there are no such a thing as HIV & AIDS. They really don't believe upon medicine tablets, they do only really believe in traditional healers.
>
> H4: …he will tell you, no, it is not the HIV, it is because someone is after us, understand?

All the men I spoke with were quick to distance themselves from belief in witchcraft or Satanism in relation to HIV:

> M3: Connected? I don't think there is a relationship between witchcraft and HIV; I don't think so. Because the HIV, it's, it's only affects you accordingly with your blood or in the fluids of the body. So it's not just by, by, by the wind or something else.
>
> M2: Nah. The Sangomas really don't understand what this HIV and AIDS, they are just going to tell you about Satanism.
>
> M4: But those people that are educated about HIV and AIDS, they know that, yah, they are no good…

Not all men however, were as willing to write-off the potential for a Sangoma to help in the case of HIV/AIDS:

> M1: I think there are things, we call herbs, …like garlic and African potato, and things. …there are people who use them, and they say, …that these things boost you immune system. And there is somebody I know, who is my friend, she has been using it, and she is fine. She got (.) her CD4 count was I think, close to 100, but now I think her CD4 count has gone up tremendously because of using only herbs. Mixing herbs together. CD4 has just gone up, and it works, those herbs, if you know the right combinations.

One man began disparaging traditional medicine, and then later reversed his opinion:

> M6: I am having that little bit of doubt of (.) of disbelief, you know? [Interviewer: Disbelief of?] In those medications that they are using, especially in this case of HIV.
>
> The Sangoma maybe (.) they can do something because they are recognised in South Africa, and they can do something, if, as they

> have a, erm, the organisation. Yes to they can do something, I must agree. Because the government did recognise them.

This last comment may reveal a confusion, possibly arising in part because of the unclear government stance on HIV/AIDS, characterised by mixed messages.[2]

In terms of understanding how men's utilisation of traditional healers impacts on access to ARVs, the following comments are instructive:

> H3: They only come to western medicine when they say, now he is finished and then he come to the end with the herbs, and then he says ok the herbs have failed, now I can go to…[a clinic]

> M7: When the man is sick, he start to realise I must go to the clinic… But, if he doesn't sick…he must go to the Sangoma. If I have a pain in my chest, it's not nature to go to the doctor, because the doctor is going to give me a Panadol. So I must go to the Sangoma.

The first comment implies a view of the clinics as a last resort, when all else has failed. This is supported by health worker reports of men typically arriving at clinics very late in the disease process, complicating treatment. The second comment seems to imply a belief that, whereas the clinic can only treat symptoms, a Sangoma addresses the underlying problem, and so is a preferred choice. In both these case, according to one MSF doctor:

> H2: …it would be foolish try to make a picture without them. They're there and they're being consulted, and they're trusted. And I think they can play probably an important role in informing patients if they were informed themselves.

As several commentators have previously noted, this is an important approach to pursue in any forthcoming treatment plan (Department of Health 2003; Farmer *et al.* 2001).

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[2] For a more in depth exploration at this topic see Beck 2004; Nattrass 2004.

Gender and the Perception that HIV is a Women's issue as a Barrier

Despite all the men I interviewed having had education and counseling at some stage in the MSF clinics, some appeared at times confused with the specifics of transmission of HIV:

> M4: In most of the cases, it's the man who spreads the virus.
>
> M5: It's because, most of the time, it's only, the, the women who become sick…they are always…carriers of this disease, yah.
>
> M2: Women are more afraid of the virus, they get more infections like thrush, that is why women all go to the clinic, but men do not have these problems.

It is these last comments that are felt by one female health worker at the MSF clinic to be the more dominant view. Her opening words in our discussion were:

> H4: Ok. Men don't come for treatment, because they think that it is a sickness of the women, HIV is a sickness of the women, it comes from the women, understand?

This attitude is potentially very harmful to efforts to increase male clinic attendance. If HIV is believed to be a women's problem, men may remain unaware of the risk they are at, or they might be inhibited from seeking help for fear of stigmatisation. One man seemed to relate physical strength with ability to prevent infection:

> M3: And you as a man, you are stronger that a, a, woman, in yourself. We might be HIV positive, me and my girlfriend, but when we are going to test, it is only my girlfriend who become HIV positive. I become negative...because I am stronger than the woman.

One cultural norm is the separation between men and women. If clinics are seen as the realm of women, attended and staffed by women, men might be prevented from attending:

> H2: Because it is a very separate culture, and I think men…well if you go into a shebeen [township pub] here, you will find men between men, and some women come round, but all the discussions, lots of the discussions happen between men.

> H3: Yes, its normal, men discussing problems with men, but not men discussing problems with women… Because in our culture…even if there is a ceremony men used to just be by themselves and…the women belong to the other side and the men belong to this side…

> H3: [The clinics are]…more female dominated, like, nurses, …so men don't like to be[laughs] exposed to, er, to succumb to women. So that is why they are less likely to go to the health facilities, like, because they are more likely to be attended by women…

If more men occupied roles as counselors and nurses, men may be more likely to attend clinics for, as posited by one male nurse, 'if they see a man's figure in a clinic, they feel more comfortable.' (H3)

Building on the theme of men feeling unable to talk openly with women present, the subject of all-male support groups was raised independently by two men and one doctor, and drew interesting responses when proposed to other interviewees.

> M1: I think that… there is a need… for a support group, for men… who are positive to come out and encourage other men…

> [Interviewer: How can we change the attitudes of the guys?]

> M8: There must be a support group of the guys. Only that would be the best solution.

> H2: It's a different approach. That hasn't been tried yet.

Only one health worker thought this was unimportant:

> H4: They don't find it difficult. They speak everything in the support group, they have no problem.

One man, when the idea was suggested, decided against a male-only group:

> M7: …because, in our homes, …we stay with women. So we must understand the women's problem and the man's problem and come together and find a solution… If …we take the man's support group only, so we don't know about the women's problem…

ARV myths as a Barrier

All participants knew the focus of my research was ARVs, and could therefore assume that I was indirectly an advocate of ARV therapy. True opinions of ARVs may have been influenced by a researcher bias that needs to be acknowledged. As such I heard few dissenting voices regarding ARVs. One man referred to the ARVs as: ‘ like a Disprin or a Panadol…[they] are one and the same thing according to my views’ [H8]. The overall impression I received, was that the men I spoke with were highly knowledgeable about the drugs, and believed that ARVs were of benefit, especially when they had experienced their effects first-hand, or at close quarters.

Close analysis of the material did, however, uncover a comment that perhaps alluded to a deeper mistrust of the ARVs:

> M8: What is the combination? Let’s say it’s a AZT, how many (.) how can I say, how many things are in that one tablet, a mixture of certain things (.) how many compounds upon one tablet?

In an informal conversation, one MSF health worker spoke of something she had heard that day that revealed a common myth about ARVs. Before I turned on the tape-recorder, she told me about a patient who came in complaining that the ARVs he had just started taking had left him impotent:

> H5: Yeah, it is interesting…I asked the doctor…and we checked all the books for possible side effects of the drugs and we said it is definitely not the drugs, but this guy said that since he started the ARVs. But then the counselor said it to me when he left the room, ‘I hear it everyday from the men’ ... Obviously people will talk outside in the community. If you use ARVs you will become impotent, so don’t use ARVs, because what is more important, sex or ARVs?

The public can also misconstrue qualifying comments in the treatment literature, describing side effects and toxicity arising from the ARVs. As one doctor commented:

> H1: …some people also are actually anxious to start because of bad press… worried about side effects, worried about toxicity, heard bad reports, people hear all kinds of things. When you start the drugs you will get sick.

An HIV positive lady at an HIV clinic confirmed this to me commenting albeit in jest upon being told she was about to start her ARVs, ‘ah, they will make me sick!’

Common myths of this nature can have a large detrimental impact on acceptance of ARVs. Further research is needed that attempts to quantify the extent of these myths. Suggestions related to targeted education campaigns will be discussed in the conclusions.

Employment as a Barrier

The most commonly expressed concern regarding men coming for treatment was the problem of employment. This issue raised factors of disclosure, stigma and logistics. One doctor commented, ‘they all have the impression they will be fired if they are absent from work [whilst attending regular clinic appointments].’ (H2) A slightly different angle was taken by the men of the focus group, who expressed a fear that should a man disclose to his employer, rather than being dismissed: ‘Maybe they would put a lot of pressure on him.’ (M1) It seemed that employers, fearing that HIV positive staff are unable to perform their jobs satisfactorily, would increase their work-load as a test. Should a man decline from informing his employer, a monthly trip to the clinic and hence regular absence from work would arouse suspicion. A counselor at the MSF clinic talked of arrangements in place to counter these problems:

> H4: ‘[If you] tell us that, okay, I will be leaving at 9 to go to work, then we will start with you and then you can go to work.’
>
> H4: ‘if …they are healthy, …they are just living with the HIV, they do send their treatment assistant to come and collect their treatment.’

As attendance is essential at the commencement of treatment, the second suggestion does not fully address the issue. Likewise, if, as is hoped, male attendance increases, it is unlikely, within the current framework, that all working men could be seen before work.

Several suggestions were made to address this issue:

> M1: [If] the clinics could be available in the workplace…
>
> M1: …you can have the clinics on Saturdays and Sundays, and put more incentives for doctors and nurses to work…people who are working can go on these days.

Moving the goalposts: Examining the emergence of a ‘positive’ masculine identity

The previous sections have focused on beliefs, expectations and situations as barriers to male ARV clinic attendance. This section however attempts to explore the range of masculinity I experienced within the Xhosa culture, and to demonstrate the inadequacy of stereotype. It will be argued that an emergence of a new masculine identity is observable, one that has reconciled positive HIV status with masculinity. Further, this identity can contribute to overcoming several areas where barriers are a problem, but perhaps attention needs to be paid to the resilience and consequences of this emerging identity.

Interviewee’s portrayals of men often focused on the typical masculine traits described above. In stark contrast to these depictions were the men themselves and how they described their own thoughts and situation. Far from the man in denial, fearful, ignorant and stubborn, these men were knowledgeable about their disease and proud to be open about their status.

Research has been done by authors such as Catherine Campbell on the creation of new identities of people living with HIV (Campbell 1997). In unpublished work by Soskolne *et al.* (2003) the creation of positive identities were documented among a group of HIV positive, South African township women ,who were on antiretroviral therapy. They observed how a highly stigmatised group actively constructed a positive identity from notions of empowerment, knowledge and wellness. They noted how ‘positive representations of self also seemed to serve as a defensive function, limiting emotional knowledge of more frightening aspects of having HIV/AIDS’ (*Ibid*: 20). These pieces of work are useful in illuminating the conflicting accounts of male behaviour in the material. All the men I interviewed regularly attended a clinic, a support group or both. As such, they represent a minority in Khayelitsha who have acknowledged their positive HIV status.

From my discussions with men, it appeared that their identity had, at its core, discourses of strength and knowledge:

> M5: It is better to know, than the person that knows nothing. Because he is on the dark. You see. He is on the dark.
>
> M3: You feel stronger, as if you know everything, you see?

That strength stems from knowledge about one’s HIV status poignantly contrasted with the previously voiced idea of strength, one that manifests itself in a man refusing to acknowledge his HIV status as it implies weakness or illness and doesn't fit with the ideal image of a strong man.

Knowledge was used as a means of drawing a distinction between themselves and an ignorant 'other'. This phenomenon has been described by Joffe (1999) in other marginalised groups. As Soskolne *et al*. (2003: 11) noted of a similar observation among HIV positive women, this served to 'reinforce and assert the advantages of their own position'. This 'othering' strategy did not speak about HIV negative people as the obvious other; they instead positioned themselves against those people who are ignorant of HIV and of their own status.

> M1: I also think so, because the township people, this is what they talk about, what they think, you see…
>
> M8: Some of them is well educated some off them is uneducated you see, they need a little bit of counseling every day that's why…there is a greater difference between an uneducated person and a educated person…because he can except it because he knows what is happening throughout the world.

Just as the men I spoke with had collectively moulded a new manifestation of strength, so had they done with the masculine virtue of responsibility. In the section on culture, we saw how, during rites of passage, males were lectured on the responsibilities of manhood, and how they must provide and care for their families. Later, we saw how sickness and HIV/AIDS disable a man from fulfilling these responsibilities, and how this is construed as failure. From the material, however, emerged several references to responsibility, but framed in a context of living with HIV:

> M6: A man is someone who is reliable. Someone who had a vision. Someone who reach…you see, someone who doesn't run away from his, er, problems facing him. It's all about, how you say, a commitment.
>
> M1: …responsible men know that they must wear condoms.
>
> M6: Yeah. Because you are not running away from you responsibility. You accept your responsibilities…

This 'positive' identity, serves a dual purpose of firstly removing themselves from painful discourses of stigmatisation, and secondly placing themselves instead, in ideas of strength, knowledge and responsibility- all traditionally aspirations of Xhosa manhood.

This positive identity can clearly contribute to coming to terms with a positive diagnosis and attending a clinic. However, on closer inspection, some aspects of this identity do not seem that different from the one ascribed to the ignorant ‘others’. As with Soskolne *et al.’s* (2003) experience of a positive identity amongst women, there was little room for a state of sickness or ill-health within the new positive identity. In fact, it seemed as if a vital keystone for this new identity was a concept of living healthily with HIV:

> M2: Yah, it’s so very good to be HIV positive, because… [It’s …?] …good, good, good. It’s a good health. You are just obtaining a good health when you are HIV positive. You do have, er, new friends, who are also experiencing the same thing just like you.

Given the very real losses and illnesses of living with HIV, irrespective of ARVs, there is a need to recognise the frailty of this identity. As with the classical portrayal of the Xhosa male, self-concepts of strength and good-health may make admitting sickness and seeking help problematic. Soskolne *et al.* (2003) argue that this identity, in part, stems from ‘positive living’ campaigns by activist groups. These projects are aimed at destigmatising HIV/AIDS and raising awareness of treatment options. Without detracting from the vital importance of these activities, perhaps careful attention should be paid to the long-term impacts. In this way, more stable, resilient identities may emerge, centred more on responsibility and self-care, instead of existing purely as an ‘inoculation’against stigmatisation based on ultimately unrealistic concepts of strength and health (*Ibid* 2003).

Conclusions

Within South Africa, men, as a group, fail to overcome barriers to access to ARV clinics (Coetzee and Nattrass 2004). Situated in the wake of an announced Operational Plan for Comprehensive Treatment and Care for HIV/AIDS, centred around free ARV provision, and before this programme is fully implemented, this research sets out to better understand the problems that men face.

This research project set out to explore men's experiences of HIV/AIDS and attitudes to ARVs with the aim of understanding perceived barriers to accessing treatment, and the reasons behind these. In this way, it was hoped that a better understanding could be grasped of how to make ARV treatment programmes more accessible to men.

Analysis of the material revealed a number of barriers, on an individual level, within a cultural context, and on a practical level. Often these levels merged to produce a picture that required dissecting.

The effects of stigma were explored, revealing that due to factors such as employment and cultural expectations, stigma appears to affect men more than women. Suggestions were made to combat this situation, such as separate back doors into the clinics so men would not be seen. It was felt that with the planned incorporation of HIV services into the mainstream health services, HIV stigma was not here to stay.

Pursuing cultural expectations, a barrier was recognised in the shape of rigid roles and responsibilities inherent in being a Xhosa man. These expectations led men to outwardly convey a picture of health and ability, and therefore inhibited men from seeking help.

Men felt under pressure to embody characteristics associated with Xhosa masculinity and periods of ill-health associated with HIV caused a collapse of this constructed identity. It was observed how some men in this position sought to reinterpret elements of this ideal man, such as attributes of strength and responsibility, as well as feelings of good health associated with awareness of one's HIV status. In this way, a new male identity was formed, shielding the man from stigmatising discourses.

The significance of traditional medicine and the role of the Sangoma, or traditional healer, were explored, revealing that men often consider a Sangoma a first port of call in times of sickness. Some attributed this to a belief that western medicine treated symptoms, while the Sangoma addressed the underlying cause. It was also suggested that a Sangoma should be able to meet all the health needs of an ideal Xhosa man, and defecting to a western doctor indicates weakness. Given the trusted status of Sangomas, health workers suggested an approach that worked with them, utilising their elevated position, and suggested that if education efforts were aimed at these individuals and they in turn either educated people or referred them on, perhaps some barriers to men's attendance at ARV clinics could be broken down.

Ideas about gender were also explored in relation to beliefs about HIV. It was found that men often considered HIV/AIDS, not only a condition that affected women more commonly than men, but one that was more severe for women too. As such, clinics were viewed as the realm of women, both attended and staffed by females. One male nurse advocated recruitment of more male counselors and nurses as a means of addressing this. Clinics and support groups dominated by women were also cited as a problem due to the tradition of gender separation. It was felt that men tend to share their problems among men and feel uncomfortable discussing sensitive issues with women present. Numerous people suggested male support groups, where it was hoped men could share their views and experiences and encourage more men into ARV therapy.

Myths surrounding ARVs were mentioned, although their pervasiveness was not established. It was felt that at the root of the myths lay misinformation and a lack of education. One health worker suggested creative health education projects in shebeens (township pubs), as a means of reaching men.

Despite high levels of unemployment in Khayelitsha, one regularly voiced problem centred around working. It was felt that men who worked were often unable to attend clinics for a variety of reasons including fear of disclosure to employers, and being unable to visit the clinic during working hours. Despite some provisions already made for these men, it seemed the problem has not been satisfactorily resolved. Suggestions to address these problems included clinics in the workplace and weekend opening of clinics.

The emergence of a 'positive' masculine identity was a discovery of special interest. There is clearly value in attempting to ground a positive HIV status in discourses of strength, knowledge and responsibility, and it also serves to encourage disclosure and fight against problems of denial and stigma. Nevertheless, it was felt that this 'positive' identity may have problematic and unexpected consequences, as foundations of the identity appear rooted in ultimately unrealistic concepts of strength and good health. Future research that centres on what Soskolne *et al.* (2003) refer to as 'positive identity work', would be justified in the context of these men living with HIV/AIDS. One doctor suggested an aim for future interventions of this kind and it seems fitting to end with his words:

Try to have this image of the fact that disclosing, being open about your HIV, treating yourself, is something courageous, that taking responsibility is something masculine, that is very important, and according to me it is. I think [people] who don’t test because they are scared, they are sissies! I think that if everybody was thinking that in Khayelitsha, much more men would come to test. I don’t think we need to use a negative approach, but you can show how responsibly some people can act… (H2)

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