

Narratives of HIV disclosure and masculinity in a South African village

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This paper describes men's experiences of disclosing their HIV status, arguing that disclosure restored their social respect, which was previously undermined by an illness from AIDS. Results are from a 14-month ethnographic study conducted in rural South African health facility, among a group of 25 men attending an AIDS support group. The men included in this study tested while they were critically ill and some were negatively labelled as 'already dead' because of their poor state of health. The majority voluntarily disclosed their HIV status to the public after recovering from the physical symptoms of AIDS. This elicited positive reaction from the community, who treated them with admiration for disclosing their HIV status. The paper emphasises the fact that the good response received by participants from the community was predicated mainly on having healthy physical looks that men gained from using antiretroviral medication. This paper then further analyses the ways in which a 'healthy appearance' facilitates disclosure of HIV status and also disrupts the stigma attached to HIV in the studied community.

Keywords: masculinity; black men; ethnography; South Africa; living with HIV

Introduction

In this paper I describe men's experiences of disclosing their HIV status to their intimate sexual partners and to the public. My objective is to show how public disclosure of the HIV status enabled men to restore their masculinity, which was previously undermined by the experience of being ill from AIDS. This focus (on men who have disclosed their HIV status) is an unusual trend in research on HIV and AIDS in Africa. Most studies have concentrated on how people living with HIV strive to hide their HIV status rather than publicise it (Gilbert and Walker 2010; Mills 2006; Mutimura, Stewart, and Crowther 2007; Niehaus 2007; Steinberg 2008). Participants in these studies have cited fear of stigma attached to HIV and AIDS as a main reason for concealing their HIV status. My findings, based on an ethnographic study conducted in Bushbuckridge, South Africa, indicate that men who disclosed their HIV status after recovering from an AIDS-related illness received greater social support and admiration for their openness. This boosted their self-esteem and status in the community.

To give an intimate picture of disclosure and its outcomes, I will begin by sharing an extract from my interview with Duma, a 35-year-old participant. In October 2004, Duma fell ill while working at a construction company in Johannesburg, about 500 km from his

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home in Bushbuckridge. He initially ignored his poor health and continued to work, despite being unwell. Later he consulted a traditional healer, who told him he had been bewitched. The healer gave Duma a concoction of traditional medicines to treat his condition. But he became worse and then decided to leave his job and return to Bushbuckridge to be cared for by his wife. At home he continued to use traditional medicines for four months, but to no avail. One morning, in March 2005, Duma decided to secretly take an HIV test at a clinic near to his home. He walked there alone, without telling his wife and three children. The test results were positive and Duma initially concealed them from his wife, as he explains:

I was seriously sick that time and I thought if I can disclose to her that I am HIV-positive and then she leaves me, there would be no one to care for me. Because I wasn't like the way I am now. I couldn't even move around; I had to be in one place all the time. She cooked for me and did all sorts of other things. So I decided not to tell her for the fear that she might leave me. But I was causing more damage. When I look back I feel I could have told her earlier; maybe she wasn't going to leave me.

The 'damage' that Duma refers to is the fact that his wife became pregnant during this time: before he had disclosed his HIV status to her. He said it was difficult to negotiate condom use with his wife, 'because here [at the clinic] they are telling me to use a condom, but how am I going to use a condom without telling her what the problem is?' He disclosed to her after five months of knowing his HIV status and subsequently encouraged her to test as well. She also tested HIV-positive. Their daughter was born prematurely and died in the hospital four days after birth. Duma said his partner was 'very supportive' – she did not leave him as he had expected her to do. She also told Duma to not to feel responsible for their HIV infection. A few months after disclosing to his partner, Duma disclosed to his close friends. He described them as equally supportive, 'If I have a problem I approach them and we discuss it. And they advise, "OK, if things are like this you must do like this . . ."' So they really encourage me a lot, you see.' Later I will explore how this 'support' and 'encouragement' from peers and community translates into redemption of masculinity for men living with HIV. The next section looks at the link between HIV, disclosure and masculinity as discussed in literature on these topics.

Men, masculinity and HIV

For many years in the history of HIV and AIDS research in Africa, studies of (heterosexual) men have portrayed them as drivers of AIDS because of the ways they construct their masculinities (Barker and Ricardo 2005). As a result, research that documents men's subjective experiences of living with HIV – particularly male HIV activists – has been very scarce (Lynch, Brouard, and Visser 2010). Men have been portrayed as drivers of AIDS: by having multiple sexual partners; refusing to use condoms; and gender-based violence (Campbell 2001; Leclerc-Madlala 1997; Varga and Makhubalo 1996; Walker, Reid, and Cornel 2004; Wood and Jewkes 2001). The literature has painted a generally negative picture of masculinities and their impact in lives of men (Shefer et al. 2005). Furthermore it has portrayed masculinities as static and generally overlooked the ways masculinities are changing because of challenges that men face, like unemployment and AIDS (Hunter 2004).

Recently there has been a shift towards documenting experiences of men who are resisting hegemonic notions of masculinity and engaging in safer sexual practices (see Reid and Walker 2005; Shefer et al. 2007). This includes men who are living with HIV (Lynch, Brouard, and Visser 2010; Mfecane 2008; Robins 2009a). The latter studies have

clearly shown that HIV diagnosis – especially if it follows long periods of being ill – is transformative experience for men. It changes the ways men construct and experience their masculinity, as well as their roles in society. The changes are sometimes ambiguous because men living with HIV still seek to attain the certain hegemonic standards of masculinity in their communities (for example, they want to have jobs and children) (Robins 2009a). Nevertheless, they seem to be conscious of their health needs when pursuing these goals compared to the time before they were ill.

My focus on disclosure aims to contribute to an understanding of how HIV diagnosis enables men to confront the hegemonic perceptions of masculinity in their communities. I will tackle three related topics. Firstly I explore how disclosure undermines the prevailing ‘masculine norm’ in the society where men are typically opposed to using health services (Interview with community leader). Men were also portrayed by health workers that I interviewed as being reluctant to do an HIV test and later disclose their HIV status. Their main fear was that help-seeking would portray them as weak and dependent and also subject them to control by ‘young’ women (health providers). Most ill men, then, preferred to consult traditional healers because they are older and ‘they do not laugh at you’. Similar to the aforementioned representations of men, my participants tested late. I nevertheless consider their openness about their HIV status as an important step in resisting these notions of masculinity.

Secondly I will illustrate how HIV disclosure restored the men’s own masculinity. Because they had been ill from AIDS for some time, these men lost significant amounts of weight. As a result certain community members treated them with contempt and labelled some of the men as ‘already dead’ (meaning that they are physically alive but will soon die from their illness). The sick men withdrew from social relationships because of such negative social judgements. However, after they started using antiretroviral medication (ARVs), these men experienced significant improvement in their health status. This gave them the confidence to publicly disclose their HIV results. The disclosure won them great admiration from their families, friends and certain community members, who viewed the afflicted men’s openness as an ‘unusual’ (*ayijwayelekile*) way to manage their HIV status in Bushbuckridge. Most people told me that it is ‘very rare’ (also translated as *ayijwayelekile*) for HIV-positive people in Bushbuckridge, particularly men, to openly disclose their HIV status. Hence, the men who broke from this tradition of HIV secrecy became ‘role models’ and this tag restored their social respect.

Lastly, this paper engages with the complex problem of how ARVs impacted on stigma assigned to AIDS. This focus emerged out my observation that men who used ARVs and recovered physically from AIDS consequently received good social support and admiration from the society. This was different from men who disclosed their HIV results while they were critically ill. Health, then, features prominently in my claim that disclosure restored masculinity among my participants. However, a brief discussion of literature on ARVs and their impact on AIDS stigma is necessary before I substantiate this claim.

ARVs, stigma and masculinity

Various scholars have debated the impact of ARVs on stigma attached to AIDS in African communities. For example, Robins (2005) noted that access to ARVs enabled people living with HIV to have the confidence to openly disclose their HIV status and to engage in health activism. Ashforth and Nattrass (2005) are somewhat sceptical of ARVs potential to reduce AIDS stigma, but concede that ‘... if HAART regimes turn out to be widely

successful and reduce the perceptions of AIDS as being incurable, AIDS-related stigma will decline ...' (293). Gilbert and Walker (2009) also view ARVs as contributing to 'normalisation' of HIV by improving the health status of patients. This leads to 'the potential to reduce the stigma associated with HIV/AIDS' (1126). But in their later work (Gilbert and Walker 2010), the authors intimate that stigma still persists among users of ARVs and significantly impacts on their ability to access treatment and other support services.

Other studies point to the potential of ARVs to exacerbate AIDS stigma instead of alleviating it. For example, Mutimura, Stewart and Crowther (2007, 2) discuss how ARVs produced unwanted fat redistribution syndrome called lipodystrophy. This led to self-stigmatisation as ARV-using patients reported poor quality of life and social withdrawal due to embarrassment about their physical appearance. In Roura et al. (2009) patients, whose health status improved drastically since using ARVs, experienced stigmatising responses from society. They were labelled as AIDS vectors because they were seemingly (sexually) attractive, but their HIV status was no longer physically detectable, as it was when they were ill.

Part of this paper contributes to these debates. I particularly highlight the way that physical improvement as a result of ARVs improves confidence in men: it enables them to disclose their HIV status and also facilitates positive responses from the society. My analysis of stigma, then, emphasises the fact that stigma is both an 'intrapersonal' and 'interpersonal' phenomenon (Wyrod 2011). I also agree with Wyrod, that the analysis of the impact of ARVs on stigma needs to attend to gendered experiences of AIDS-related illness. Wyrod views illness from AIDS as a deeply emasculating experience for men because of the ways it affects their capacities to fulfil their roles as independent providers for their families. This causes ill men to look for other symbolic markers of status to boost their personal confidence and social standing, such as being leaders in the organisation of male activists. Some men in his study have clashed over positions of leadership in their organisation to gain this status.

I view disclosure as one of those symbolic markers of status among my participants. In the absence of work and other traditional markers of masculinity, disclosure became a useful resource used by (previously ill) men to receive social respect and status. Because they were treated as 'role models' for their openness, these men were relieved from a felt sense of emasculation. These positive outcomes, however, depended entirely on looking healthy, as sick people were still ostracised in their families and circle of friends. Hence a significant part of my contribution to the debate on ARVs and their impact on stigma is to include the notion of appearance (Kelly and Field 1996; Stone 1962). This concept enables a closer look at interpersonal stigma attached to AIDS while not losing sight of the fact that stigma is also a highly subjective experience. My argument, therefore, is that ARVs enable men to experience HIV differently in that the medical regimen removes the felt internal sense of stigma – this builds confidence to disclose and receive acceptance based on having improved physical looks.

Methodology

The study was conducted in the rural district hospital in Bushbuckridge, Mpumalanga province. The study participants were all HIV-positive and used ARVs and were recruited from the support group of people living with HIV at the HIV clinic. The criteria for qualifying for ARVs, as set out in the government policy, was that patients have CD4 counts below 200 (DOH 2004). Most of my participants qualified immediately for ARVs

as they were already critically ill by the time they took an HIV test. I attended the support groups for the duration of my fieldwork. I interacted regularly with men and befriended some of them as a first step to recruiting them into my research. There were no strict criteria for recruiting participants, instead I approached individual men randomly outside support group and initiated conversations with them. I shared details about my research during our informal chats and then requested them to be participants. None of them declined my requests as they were already familiar with me through my sustained attendance of the support group.

In total, I interviewed 25 men aged between 28 and 50 years. Of the participants, 6 were married, 4 were cohabitating, 3 had partners that they did not live with and 12 were without girlfriends. I conducted all the interviews in local languages, Shangaan and seSwati and translated them into English during transcription. The semi-structured interviews were conducted in a private space at the hospital and at participant's homes. The trust that I built with participants through initial informal conversations and regular home visits enabled me to overcome the problem of 'impression management' that characterises most of qualitative research narratives on health (West 1990).

All interviews were guided by a list of questions about participants' experiences with HIV illness, their decisions to test and disclose their results, as well as the outcomes of disclosure. The interview process was fluid, allowing participants to digress from my list of questions and to discuss issues of interest to them. This enabled me to identify new themes to be explored in follow-up interviews and informal conversations. In addition to these interviews I also interacted regularly with family members of participants and formally interviewed some of them. Other informal interviews were conducted with community members and healthcare providers whom I met during my research. All research processes were reviewed and approved by the University of Witwatersrand ethics committee on qualitative research with humans.

The next section on findings first explores societal construction of AIDS to illustrate the impact of stigma on disclosure decisions and outcomes. This is followed by a specific focus on disclosure of HIV status by participants. To emphasise the importance of looking healthy in disclosure decisions and outcomes, I focus on 'when' men publicly disclosed their HIV status. The last section investigates the ways disclosure restored men's social respect.

'Disclosure ayijwayelekile' ('disclosure is unusual')

Most people thought of AIDS as a deadly and contagious disease. They often made no distinction between HIV and AIDS and did not recognise the fact that someone can have HIV without necessarily being ill. Having 'AIDS', then, was normally associated with being sickly and approaching death. Most people felt they can easily detect AIDS symptoms from the physical changes that ill people undergo, like weak and emaciated body, skin rash or other changes. At times these signs were interpreted as meaning that someone suffers from a disease syndrome known locally as *tindhzaka* (often used interchangeably with *sifulara*, though *sifulara* can be caused deliberately by witches). The disease is believed to be acquired by violating sexual taboos related to death (Posel, Kahn, and Walker 2007). For example it is not acceptable for a widow to have sexual intercourse during the prescribed one-year period of mourning the death of her husband. Community members who are involved in preparations for the funeral, or who ate food prepared for the funeral, are also prohibited from having sexual intercourse until three days after the burial. The breakage of these rules is believed to result in *tindhzaka* and even death. But unlike

AIDS, *tindzhaka* is thought to be a curable disease (by specialist traditional healers only) and is not contagious.

The labelling of ill and thin people as having AIDS contrasts with the view of healthy-looking people as being free from AIDS. This includes people who have tested HIV-positive. In support groups, most HIV patients claimed that other people – including their new sexual partners – dispute that they have HIV because they look ‘fat’ (*usdudla*). This view was also expressed by the recently diagnosed patients during their consultations with HIV-positive counselors at the clinic. One of the HIV-positive counselors that I conversed with explained: ‘Some of them find it hard to believe me. They look at me and say ‘*Wena usdudla so!*’ (You, as fat as you are!). Most of these new patients had tested while they were visibly ill, hence they disputed the HIV status of the counselor because she had no signs of being ill.

Because AIDS is viewed as a deadly and contagious disease it carries lots of stigma in Bushbuckridge. This results in lots of secrecy about the HIV status, even for people who are not yet ill, as this comment from a 40-year old key informant interviewee shows:

I really don’t know anyone who has ever lived with HIV here [in my village]. The only person I know is that lady from Radio Bushbuckridge. She normally talks about being HIV-positive, but not here.

The stigma attached to AIDS, however, appeared very complex and sometimes confusing to me as a researcher. It was more severe for people with visible symptoms of AIDS, compared to the healthy-looking individuals. On the other hand, I found no evidence of stigma attached to what are medically recognised as ‘AIDS symptoms’, unless people believed or knew that a person has AIDS. This was evident in how family members cared desperately for ill relatives, including men who had obvious symptoms of AIDS like coughing, bodily sores, skin rash and weight loss. They only began to openly ostracise their kin after discovering his HIV results. Before this, the family assumed that a person had *tindzhaka* or *sifulara*. To illustrate this point I share an extract from my interview with Mrs Mali, a mother to one of my participants.

Bob, a 32-year-old participant, became ill in late-2004. Once he sickened the entire family became very concerned. His mother told me they could not sleep or eat: ‘The food would just rot here; no one wanted to eat anything because he also refused food’. They took him to a traditional healer near Palaborwa town, about 100 km from his home, to get a diagnosis and cure:

These people [traditional healer] said it was *sifulara* ... you see, if there is death in the family; that’s what they said. We left him there for three days. But it didn’t work, so we decided to rather take him to the doctor.

The healer prescribed some treatment, but it did not work. Then out, of desperation, Mrs Mali suggested that Bob did an HIV test. But he was reluctant to test because he thought he had AIDS:

He refused, saying ‘if I go to that hospital they will tell me I have AIDS’. I said ‘There’s no problem; it’s better if you know so you can find a way around it, of how to deal with it’. So he kept refusing. I tried to convince him. And then I said ‘Please do this for me; would you rather die?’

After additional pleas from his uncle, Bob finally tested for HIV at the clinic. The results came back positive, his health deteriorated and his mother, who had urged him to test, reacted harshly to his condition:

I looked at him: his eyes were too white; he was very thin; here it was red; you see here [pointing at lower lips], it was red! It was so red I was even *benginyanya* (disgusted by it),

I couldn't even touch the cup that he used, I must be honest with you [laughing]. I told him, 'Now this is your own cup; this is your own jug. If they give you *mageu* (non-alcoholic beverage) you use this one. If you want water, tea, here; you know your own plate'. Then from there I took him for treatment, and he started getting better. But I have now accepted.

Interviewer: as his mother, how did you feel about separating his utensils?

I heard them saying this thing [HIV] can spread to the entire family. I didn't know what would happen. But as time went on, now that he is well [healthy] we do sit down and chat about it with him ... I say 'you know I used to be disgusted [by you] ...'

This interview underscores the widely reported tendency to ostracise people with visible symptoms of AIDS (Mills 2006; Valencia-Garcia et al. 2008). But in this study the rejection of ill people by their families was delayed. This was because family members thought their kin had *tindhzaka* and it took some time for them to change this perception and to think of him as living with HIV. Because *tindhzaka* is not regarded as a contagious disease, family members were exceedingly tolerant towards the symptoms of AIDS. The HIV diagnosis disrupted this tolerance as also reminded the carers of their own vulnerability to HIV. This led to drastic changes of attitude towards an ill person and withdrawal of emotional support and care. For sick people in general this change makes it difficult to do an HIV test and to later disclose their HIV results.

There was an additional factor for men in this reluctance to disclose their HIV status. The interviewees said it is uncommon for a man to openly reveal his life difficulties, because doing so portrays him as weak and dependent. According to this view, 'real' men deal with personal problems on their own, instead of asking for help from other people. Mr Khosa (about 55 years old), one of the community leaders that I interviewed, explained:

Amadoda vele awakhulumi [men are like that; they just don't talk]. Men are faced with so many problems. But they never talk. ... You see a man waking up early in the morning and take his cows to the field. He will stay there the whole day! He hasn't eaten anything. And when he comes back he goes straight to his home and sleeps. He doesn't talk to anyone.

My participants nonetheless disclosed, despite these fears, and I now turn to their narratives on what motivated them to divulge their HIV status.

Health status and disclosure of HIV status

The treatment guidelines at the ARV clinic encouraged HIV patients disclose to at least one person before initiating an ARV treatment programme. This person serves as their treatment supporter. Whilst most patients adhered to this advice and disclosed to their trusted relative, they delayed voluntary disclosure to other people until they recovered from an AIDS-related illness. The five men who disclosed immediately to all family members, did so under duress. Their relatives pressured them to test while they were ill and then expected them to 'report back' on their test results. The delay in disclosure of HIV status reflects a prevailing worldwide tendency among HIV-positive people to suspend HIV disclosure until they have properly weighed the potential costs and benefits of revealing their status (Green and Sobo 2000; Persson and Richards 2008). The 'losses' can be in both material and status terms (Valencia-Garcia et al. 2008).

For my participants, the fear of losing status as a man was paramount to delay of disclosure. But it was also tied to the immediate fear of losing material and emotional support from an intimate partner and close relatives. Most men worried that their partners would abandon them, family members would find them disgusting and the community would label them as 'already dead'. Disclosure became a well-calculated effort in

consideration of these concerns, as Duma, the participant I introduced earlier, shows in the next account.

Duma disclosed five months after discovering his HIV status. He was worried that his partner would abandon and label him as an AIDS vector. Duma was sickly at that time and his body had a rash. He also felt unattractive to other women. Duma said that the main motive to finally disclose to his partner was to protect her from being continuously exposed to HIV re-infection by having unprotected sex with him. But he, like many others, disclosed when he felt physically strong and emotionally prepared to withstand the rejection from his partner. He was attending support groups at the time and they gave him the confidence to look for a new girlfriend if his partner decided to leave him. He explained: 'I told myself that if she leaves me I would find another woman in the support group. There are many women in these support groups'.

Duma appears to have been encouraged by the improvement in his health status and thus finally overcame the fear of disclosing to his partner. He was not alone in approaching disclosure in this way. My interview with Tinyiko, a 34-year-old participant, similarly points to the impact of health improvement in building confidence for men to openly disclose their HIV status. Before he took an HIV test in 2005, Tinyiko had been sickly for a very long time:

It was a combination of meningitis, pneumonia and TB. So you find that starting from May, June, July, August, September, October, November, I was really sick during those months. I could see that *vele la sengiyahamba* [it's now obvious that I'm passing]. And many people were already pointing at me and saying, '*Ay lento lena sele ishonile* [this thing is already dead]'.

Tinyiko enrolled for ARVs and then committed himself to adhering strictly to treatment. This enabled him to recover physically and to then confront the stigma that he experienced while he was ill:

So, by the time I tested for the first time my CD4 count was 94; 97; 60; 35 – it was rushing; it was less than 100! So I enrolled for treatment, and by that time my CD4 count was 39. So I kept going with these pills, kept going with these pills, and I could see that this stage that I am in, I had returned to HIV and all these symptoms were going slowly, like diarrhoea. So until today I'm still just fine; I'm still surviving.

Tinyiko was initially secretive about his HIV status, even to his family members. As soon as he got better he began to openly disclose to his relatives and other people. First he disclosed to his mother and then to the community. He later partnered with the provincial Department of Health and became known as an 'AIDS ambassador' in Bushbuckridge. He openly spoke about his HIV status in community meetings, schools and in one-to-one encounters with people. Tinyiko received a good response from the public, who appeared to embrace rather than ostracise him for living with HIV. He cited his improved state of health as a contributing factor to the community's supportive responses: 'Most of them don't believe me [that I'm HIV-positive]. Some say, "*Ey wena, udla nje imali ka government* [you are just abusing government money]" [laughing].'

This sense of disbelief among the community was also experienced by other men who disclosed their HIV status. For example, Kenneth, a 32-year-old male activist, explained:

Even now, I just met this guy. . . . He said, 'Hey I didn't see you last year; where were you?' I told him I was sick and he asked 'sick from what'. I said 'HIV' [AIDS]; I was sick from HIV'. He said 'No, that's a lie; a HIV-sick person doesn't look like you'. So I just ignored him.

As I explained earlier, disclosure of HIV status is considered as an unusual practice in Bushbuckridge because people believe that AIDS (no distinction made between HIV and

AIDS in the community) is a deadly disease and that someone with AIDS will die soon. It appears that the health improvements gained from using ARVs unsettled these community beliefs. Healthy looks also created uncertainty in the community on how to react towards people living with the HIV virus. This uncertainty is tied in with intense fear of one's own vulnerability as people suddenly realise that someone living with HIV may look the same as they do. Thus the reported disputation of their HIV status, in my view, indicates the observers' anxiety about their own HIV status. It is a sign of admiration for their openness, tied to a deep-seated fear that one might also have the virus in one's own body.

Wyrod (2011) argues that despite these outcomes of ARVs on AIDS stigma, the stigma persists, particularly at the intrapersonal level, because of the fact that men are unemployed and therefore unable to fulfil their traditional gender obligations as providers for their families. His findings agree with Robins (2009a), who has shown that men living with HIV feel emasculated because they are unable to provide and be 'responsible'. Although Tinyiko, Duma and other activists were unemployed, and therefore unable to reclaim their masculinity in these traditional terms, their openness and improved health nevertheless appeared to have boosted respect for them in their communities.

Disclosure and restoration of social respect

The main reason for publicly revealing HIV status, as claimed by the participants, was to raise awareness about the seriousness of the AIDS epidemic and to encourage sick people to test and get treatment. Tinyiko said, 'I wanted to help others to see that AIDS is not death. AIDS is nothing; you can live with it for as long as you want'. Duma expressed the same motive for openly disclosing to his peers:

I tell them, 'You see, had I gone to test earlier I wouldn't have reached this stage [being ill and later on ARVs]. Because I was also scared. I used to hear them talking on radio and the clinic, saying, 'Go and check yourself, go and check yourself', but I was scared. And I ended up being sick, and it's only then that I decided to go and test.

The vital outcome of this activism is that it enabled men to gain admiration from the community in a ways that seemed to enhance their social statuses. In particular, these outcomes were achieved because of doing something considered by most people as unusual (*ayijwayelekile*). Interestingly, disclosure no longer seemed to reflect 'weakness' or dependence on the part of men, as is reportedly the case for men who share their secrets, instead it became a mark of strength. Openly HIV-positive men earned esteem from their peers for testing and then disclosing their HIV status and were seen as 'strong'.

Duma said he gained lots of respect from his friends for doing an HIV test and disclosing his HIV status to them. He described his peers as being 'scared' to test. He said they envied him for having already tested for HIV:

They say they are still thinking about it, that it might happen that they go and test and maybe they are found to have HIV. Now they will have stress and all that. I tell them, 'guys, this thing is not a killer. As long as you know that you are HIV positive, you must accept it'. They say, 'Eh, it's hard to go and test'. But I tell them, 'No guys; it doesn't help to just sit while you don't know your health status. You must know what's happening to your own health'.

Tinyiko reported similar outcomes after disclosing his HIV status and participating in HIV activism. He said that disclosure made him a local 'celebrity' who is sought after by the government, community leadership and 'outside tourists'. He interacts regularly with these actors who regard him as a local 'AIDS ambassador'. I first met him in support groups. He was carrying photos of himself taken with two males 'from Germany' to show to other support group members. The photos were proof of his international recognition as

an AIDS ambassador. In one community meeting that we attended together he sat in front, next to the community leader, who introduced him as 'our important guest'. Tinyiko was given a slot to disclose and educate people about HIV. These 'achievements' appear to have boosted Tinyiko's status in the community. He gained more respect and recognition from the community compared to the time before he got ill.

Other men who were admired by their peers and family members include Mathe, a 37-year-old participant. Here I include an extract from my interview with his brother, Jabu. He regarded Mathe as his role model for being open about his HIV status. This prompted him to also test for HIV:

I had those thoughts 'I will never do a blood test!' But as time went on I felt 'I would rather do blood test too, and if I do have this disease I will just accept it'. My mind changed after seeing what my brother went through. So I also attended some meetings [support groups] and I realised 'No, man; having this disease doesn't mean one will die'. Because that's how we thought of it, that 'if you have HIV it means you will die'. But I realised 'No man, a blood test doesn't mean I will die immediately'. One can live with this thing for a very long time, as long as he takes treatment.

The improvement in health status of these men, then, changed the ways people think about AIDS and judge people living with HIV. AIDS is no longer viewed as a deadly disease, but as something that one can overcome and live longer if one adheres to ARV treatment. Jabu tested HIV-negative but continued to attend support groups with his brother at the HIV clinic, to gain more knowledge about HIV and AIDS. Later, he also became a health activist. He recruited his ill cousin to clinic to test, but said the latter was 'still scared' to test.

Conclusion

For many years in the history of AIDS, men have been regarded as drivers of the epidemic in African communities (Barker and Ricardo 2005). However, current interventions view men as partners in fighting the epidemic (Peacock et al. 2008). Some of these interventions have involved men who are living with HIV. They become activists who recruit other men to test and to also educate HIV-positive men to live responsible lives (Colvin and Robins 2009). To perform these roles, men normally disclose their HIV results, either to the public or to specific men whom they are targeting for help.

For men, disclosure of their HIV status is not just a routine matter of revealing the test results for purposes of activism. Some authors view it as a sign of resistance to hegemonic constructions of masculinity (Lynch, Brouard, and Visser 2010). In this paper I have explored disclosure and its association with subverting certain notions of masculinity pertaining to help-seeking behaviour by men. I have also looked at its impact in restoring the previously undermined status of HIV-positive men. In exploring these ideas, I paid particular attention to (physical) health (or appearance) and argued that it was a main facilitator of disclosure of HIV status. It also played a crucial role in shaping the positive responses of the public towards a disclosing person. Because of looking healthy, men were not viewed as a threat to the well-being of other people and this facilitated their acceptance in the society.

The findings can inform the ongoing interventions aimed at involving men living with HIV as AIDS activists. Most AIDS activists encourage people living with HIV to challenge social AIDS stigma by publicly embracing their HIV status (Robins 2005; Whittaker 1992). This is not limited to AIDS, as research on other illnesses and sexual identities has shown that 'coming out' is frequently associated with disruption of stigma

and shame attached to these conditions (Persson and Richards 2008). But disclosure is also dependent on having a supportive environment to come out to, as Persson and Richards remind us. The heterosexual men in their study were reluctant to openly disclose their HIV status as they felt that the public did not understand their HIV situation because they believed that HIV is a virus acquired by gays and drug users. They disclosed to a selected few and, in doing so, forfeited the opportunity to educate the public about HIV and AIDS.

These supportive conditions are particularly important for men, as disclosure inevitably entails confronting the traditional societal definitions of masculinity, like the beliefs that real men are strong, independent and do not seek medical help. In this capacity, disclosure may lead to confrontations between activists and their peers, who prefer to deny their health needs as a way to maintain a 'strong' and 'independent' front. According to Robins (2009b), HIV treatment activists received harsh resistances from their communities when they attempted to change communal traditional beliefs about AIDS.

Interventions need to broaden their focus and also aim to educate men in a community about the importance of attending to their health needs and of supporting other ill men. This will ensure that, when HIV-positive men disclose their status, they do not enter into unfamiliar terrain defined by silences over the health needs of men. It will also enable sick men to disclose and gain support from their families and peers and to dispense with the internalised stigma of being ill, as noted by Wyrod (2011).

Men who are living openly with HIV can become role models for other men who want to change and lead responsible lifestyles as a way to lessen their risks of contracting HIV. Already these men have made an impact among their peers and family members in raising awareness about the seriousness of HIV and AIDS and the need to test and know their HIV status. Interventions need to build on their achievements and aim to involve more men in HIV activities, like testing, HIV disclosure and health activism. But interventions also need to provide men living with HIV with emotional support and counselling to enable them to cope with other challenges, like unemployment.

The limits of these findings are that they are based on experiences of men who have publicly embraced their HIV status and have improved significantly from using ARVs. Further studies need to also investigate experiences of men who stopped using ARVs, to determine if their decisions to stop treatment impacted on their disclosure decisions as well as their sexual conduct.

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Résumé

Cet article décrit les expériences des hommes qui dévoilent leur séropositivité au VIH, et soutient que ce dévoilement leur permet de restaurer une certaine reconnaissance sociale, précédemment ébranlée par une maladie associée au sida. Les résultats présentés sont ceux d'une étude ethnographique d'une durée de quatorze mois conduite dans un établissement de santé de l'Afrique du Sud rurale, parmi vingt-cinq hommes participant à un groupe de soutien pour les personnes atteintes du sida. Les hommes inclus dans cette étude ont été dépistés pour le VIH alors qu'ils étaient gravement malades, et certains d'entre eux ont été péjorativement qualifiés de «déjà morts» en raison de leur mauvais état de santé. La plupart d'entre eux ont volontairement révélé leur séropositivité publiquement, après s'être remis de leurs symptômes associés au sida. Ce dévoilement public de leur séropositivité au VIH a entraîné une réaction positive de leur communauté qui les a traités avec admiration. L'article souligne que cette attitude positive de leur communauté vis-à-vis des participants était fondée principalement sur le fait que ces hommes montraient des signes d'une bonne santé, obtenus grâce aux médicaments antirétroviraux (ARV). Ensuite, l'article analyse, de manière plus approfondie, comment «l'apparence d'une bonne santé» facilite le dévoilement de la séropositivité au VIH et fait barrage au stigma associé au VIH qui existe dans la communauté où s'est déroulée l'étude.

Resumen

En este artículo describimos las experiencias de hombres al revelar su condición de seropositivo y argumentamos que esta revelación restablece su respeto social que antes estaba socavado por una enfermedad a causa del sida. Los resultados fueron recabados de un estudio etnográfico de catorce meses de duración que se llevó a cabo en un centro sanitario rural de Sudáfrica entre un grupo de veinticinco hombres que asistían a un grupo de apoyo para afectados del sida. Los hombres incluidos en este estudio se hicieron la prueba cuando estaban gravemente enfermos y algunos fueron calificados negativamente como 'ya muertos' debido a su mal estado de salud. La mayoría reveló voluntariamente su condición de seropositivos al público después de recuperarse de los síntomas físicos del sida. Esto aportó una reacción positiva por parte de la comunidad que los trató con admiración por haber revelado su condición de seropositivos. En este artículo ponemos de relieve que la buena respuesta que los participantes recibieron de la comunidad se basó sobre todo en que los hombres presentaban un aspecto físico saludable gracias a los tratamientos con antirretrovirales. En este artículo analizamos además de qué modo el hecho de tener un aspecto sano facilita la revelación de la condición de seropositivo y también altera el estigma asociado al VIH en la comunidad estudiada.