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WHY DO PEOPLE DISCLOSE THEIR
HIV STATUS? QUALITATIVE EVIDENCE
FROM A GROUP OF ACTIVIST WOMEN
IN KHAYELITSHA

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Abstract

This study explores the bio-psychosocial context of HIV/AIDS in which eleven HIV-positive activist women from Khayelitsha negotiate the process of disclosing their HIV-positive serostatus to significant others, specifically biological household members. The study is based on the narratives of a group of HIV-positive peer-educators in Cape Town, South Africa. The results suggest that people's perceptions of HIV/AIDS are shaped by a wide variety of factors including: the context-laden nature of HIV/AIDS stigma in their communities; their understanding of the source of illness and misfortune; the prevalence of AIDS-denialism in South Africa; the availability of life prolonging highly active antiretroviral therapy (HAART), and their exposure to 'treatment literacy' and HIV/AIDS-education initiatives. The decision to disclose HIV status to others occurs within this shifting web of meanings, and in turn, reshapes them as people respond to the person who has just disclosed. Eight out of the eleven women disclosed to a close biological household member (significant-other) as significant-others provided, or had the potential to provide the appropriate support. Six of the eleven participants disclosed during the symptomatic phases of HIV/AIDS, while five were asymptomatic at the time. Four of the five who disclosed when asymptomatic were diagnosed while pregnant and had never experienced severe opportunistic infections. Additionally, these same four disclosed some time after diagnosis (nine months > t < two years). Of the six who disclosed in a state of ill-health, five disclosed immediately after diagnosis. At this time, concerns regarding health and mortality superseded fears of rejection and discrimination due to AIDS-related stigma. The perceived potential benefits (social and health-related support) outweighed the perceived risks (stigmatisation and discrimination). When participants had never experienced serious illness, they disclosed in order to educate loved-ones, gain emotional support or challenge false popular perceptions of HIV/AIDS. The motivations for disclosure and the choice of recipients are based on a complex and subjective combination of countering false popular perceptions of HIV/AIDS, and accessing appropriate treatment, care and support.

Introduction

This paper analyses the narratives of a group of HIV-positive women from Khayelitsha¹ who disclosed their HIV-positive status. The study combines primary qualitative data with relevant local and international research to explore the biophysical and social contexts that shape, and in turn are shaped by the disclosure of HIV status to others. The data was generated through in-depth interviews, focus-group discussions, ethnographic observation, and a self-administered questionnaire.

The majority of the international academic literature on disclosure relates to the experience of men who have sex with men (MSM) and injecting drug users (IDU) in the industrialised nations (Chandra *et al*, 2003). More recently, studies have also been conducted amongst immigrant populations (Sowell *et al*, 2003; O'Brien *et al*, 2003) as HIV infections are increasing. There is also a small emerging literature on disclosure in developing countries (see Medley *et al*, 2004) and in South Africa (Soskolne *et al*, 2004; Kahn, 2004, Matthews *et al*, 1999; Norman *et al* 2005; Almeleh, 2004; Brandt, 2005).

This paper contributes to this literature. In an earlier paper (Almeleh, 2004), I analysed the Longlife AIDS-art advocacy intervention that culminated in a book *Longlife: Positive HIV Stories* by Jonathan Morgan and the Bambanani Women's Group (2003). That study explored the ambiguities of public disclosure, highlighting the complex dialectical relationship between the activist and private lives of the Bambanani Women's Group. The *Longlife* intervention's activist and advocacy agenda was based on some form of 'public' disclosure. The individual women from the group defined 'public' subjectively and dynamically in order to minimise the risks on their personal lives. The in-depth interviews illustrated the way in which specific 'publics' were perceived according to spatial and racial considerations. In general, the women felt more comfortable disclosing outside their individual communities (within Khayelitsha), and in other areas where the possibility of identification was minimal. This data highlighted that perceptions of social distance mediated the public disclosure process. In this way, they could contribute to the struggle against HIV/AIDS, and minimise risks within their private lives in their communities.

Both this paper and the Almeleh (2004) study use qualitative data drawn from in-depth interviews with eleven HIV-positive African women and material published in the *Longlife* book. Further data was gathered using a self-

¹ Khayelitsha is the largest African township in the Western Cape, where over one quarter of women attending antenatal clinics in Khayelitsha test positive for HIV (Shaikh and Abdullah *et al* 2003).

administered questionnaire.² This paper explores, compares and discusses the participants' experiences of living with HIV/AIDS. It probes the participants' experiences of: community views on HIV/AIDS and illness; the disclosure process; initial motivations to disclose to household members; and the consequent reactions.

Overview of the literature

Studies on disclosure in both developed countries (Greene *et al* 2003, Petrak *et al* 2001, Petronio 2002, Serovich, 2000, 2001, Schmidt and Goggin 2002) and developing countries (Almeleh 2004; Chandra *et al* 2003; Soskolne *et al* 2003; Kahn 2004) show that the decision to disclose is generally a difficult process. People living with HIV are confronted with many factors that compel, encourage or constrain the decision to disclose their HIV status (Almeleh 2004; Greene *et al* 2003; Petrak *et al* 2001; Serovich, 2000; Holt *et al* 1998).

Numerous studies have shown that perceived negative reactions discouraged people from being open about their HIV status (Kalichman *et al*, 2003; Bharat and Aggleton 1999; Chandra *et al* 2003; Greene *et al* 2002, Alonzo and Reynolds 1995; Soskolne *et al* 2003; Kahn 2004; Burgoyne 2005; USAID/Synergy 2004). People Living with HIV/AIDS (PLWHA) have been shown to be more stigmatised than those with other diseases such as cancer, coronary disease and leukaemia. In most cases, fear of stigmatisation is due to the potential negative consequences of being identified and labelled as HIV-positive when either accessing treatment or support (*Ibid.*). When a person receives a positive HIV diagnosis, fear of stigma and discrimination as well as fear of early death is likely to occur (Rohleder and Gibson 2005). As a consequence of these psychosocial fears, PLWHA generally keep their diagnosis secret and carry on living as they did previously (Paxton 2002). Cline and Boyd (1993) point out that, "the dilemma faced by persons with HIV/AIDS is this: either risk becoming stigmatised by disclosing their condition, in order to take a chance on gaining the potential health benefits of social support, or avoid being stigmatised by engaging in information control and nondisclosure, thereby losing the potential health benefits of social support" (*Ibid*: 132).

Fear of stigma is an important contextual factor for disclosure in South Africa. The media and the AIDS-related stigma literature in South Africa often cite anecdotal accounts of people who have disclosed their HIV-positive status publicly and have consequently experienced some form of HIV/AIDS-related

² Tables 2 and 3 show key information obtained from the data used for this study (see below: Table 1: 'Relevant details of study participants'; Table 3: 'Context and motivation of initial disclosure to significant others').

discrimination. The most prominent of these stories are: Gugu Dlamini who was stoned to death by her community for disclosing publicly (*Sunday Times*, 1998); Nkosi Johnson who was not allowed to attend a specific school (*Mail & Guardian*, 2001); Lorna Mlofane who was raped and then murdered when she disclosed her status to her attackers in Khayelitsha (www.fin24.co.za); and Mpho Motlounq who was murdered with her family by her husband who then placed a sign on her that read “HIV-positive Aids” (TAC 2000).

These stories are constantly broadcast publicly through the media and they highlight some of the very negative social contexts faced by people living with HIV in South Africa. They are thus likely to exercise a disproportional effect on the disclosure decisions of people living with HIV/AIDS. However, it is important not to generalise too quickly from these highly publicised events about the level of stigma in society. Even as early as 1999, in a study conducted with HIV-positive women in out-patient clinics around Cape Town, South Africa, of the 51% of respondents that had disclosed their status to at least one person, 89% reported either no change or an improvement in relational quality (Mathews *et al* 1999). A recent literature review of disclosure in developing countries reported that most responses were positive (Medley *et al* 2004). Similarly, in the AIDS and Society Research Unit (ASRU) survey³ of adults on anti-retroviral (ARV) treatment in Khayelitsha conducted in 2004 and 2005 (n=247), rates of disclosure were high, with the overwhelming majority of the respondents disclosing to household members and receiving expected positive support. This has obvious social and psychological benefits for those who have disclosed. As the psychology literature shows, disclosure usually has a positive relationship with psychological well-being, as disclosure is thought to lower stress levels, which leads to better psychological health (Pennebaker *et al* 1990; Schmidt and Goggin 2002).

As LeClerc-Madlala reminds us “AIDS is more than a simple biomedical entity, it is also a cultural construction ...heavily laden with meanings that shift, expand and change as the epidemic grows” (2001: 38). People’s perceptions of AIDS are no doubt shaped by a wide variety of factors including: the context-laden nature of AIDS stigma in their communities (Deacon *et al*, 2005); their understanding of the source of illness and misfortune (Ashforth, 2005) the questioning of conventional science by the South African government (Natrass 2006); the availability of life prolonging highly active antiretroviral therapy (HAART), and their exposure to ‘treatment literacy’ initiatives by organisations like the Treatment Action Campaign (TAC) (Ashforth and Natrass, 2005). The decision to disclose HIV status to others occurs within this shifting web of

³ Khayelitsha Select Panel Survey (KSPS), see http://www.cssr.uct.ac.za/asru_research.html for more details.

meanings, and in turn, reshapes them as people respond to the person who has just disclosed.

Greene *et al* (2003) argue that fear of stigma contributes to HIV-positive people setting up defensive ‘boundaries’ around their private information. Greene *et al* (2003) have developed a comprehensive conceptual framework for analysing HIV-status disclosure based on Communication Privacy Management theory (CPM). CPM postulates that individuals develop rules for managing their privacy boundaries (*ibid*; Petronio 2002). When private information is disclosed to a trusted individual, he or she enters the privacy boundary. If the trusted person tells other people, however, the person who initially disclosed the private information will experience ‘boundary turbulence’. CPM acts as an organisational principle for many of the issues surrounding the disclosure process.

Most approaches to disclosure recognise that advantages and costs are involved. Positive motivations for disclosure include: access to social support, prevention and education, succession planning, seeking appropriate medical treatment and care, lower risk behaviours, stress relief, relational benefits (*Ibid*. Serovich, 2000, 2001). Negative factors include fear of ostracism by community or household, moral judgement and blame, relationship termination, discrimination and in some cases verbal and physical abuse (Almeleh 2004; Chandra *et al* 2003).

One of the important contextual factors shaping HIV disclosure is the biophysical trajectory associated with HIV disease. As shown in Table 1, a person infected with HIV goes through several ‘stages’ (as defined by the World Health Organisation) of illness. Exact progression times vary across individuals and are strongly influenced by socio-economic context (Gallo *et al*, 2006). As the immune system becomes increasingly compromised, the individual experiences more and more opportunistic infections, is less able to hide his or her disease from others, and is more in need of care and support. Thus, as the biophysical trajectory plays out, the individual’s social relationships change (Serovich 2001; Petronio 2002, Holt *et al* 1995). Alonzo and Reynolds (1995) have thus conceptualised living with HIV as a bio-psychosocial experience, a dynamic movement between a biophysical disease trajectory and a ‘psychosocial stigma trajectory’. However, unlike the disease trajectory, the accompanying social trajectories are fluid, context specific, and are the product of dynamic interaction between the individual and his or her social sphere. As

Table 1: World Health Organisation (WHO) Clinical Staging System for HIV Management

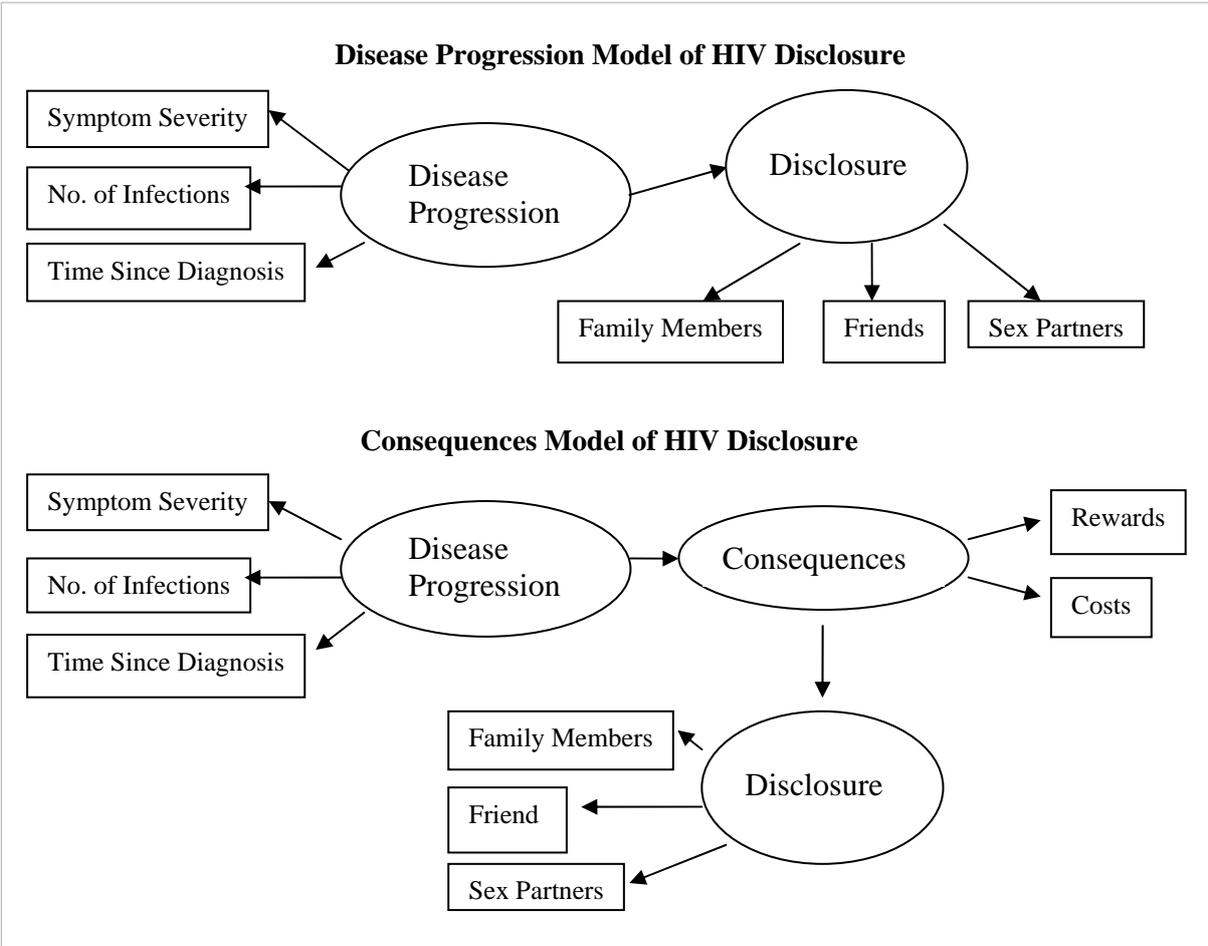
| Stages | Description | Time | Physical experiences/symptoms |
|---------------------|--|---|--|
| Stage 1 | Initial infection | 0 – 4 weeks | <ul style="list-style-type: none"> The patient has no symptoms, appears well. |
| | Seroconversion | Four to sixteen weeks after infection | <ul style="list-style-type: none"> Many patients have no symptoms. 50% - 80% of patients have a 'flu-like' illness lasting 1-2 weeks. In these patients, symptoms include swollen lymph glands (nodes), high temperature, headaches, sore throat and fatigue. |
| | Asymptomatic phase | More than 16 weeks after infection | <ul style="list-style-type: none"> The patient has no symptoms and appears well. Persistent lymph node inflammation may occur due to the high numbers of new lymphocytes being made in the lymph nodes. This stage of the disease may continue for many years. |
| Stage 2 | Mildly Symptomatic | Average period of more than four years | <ul style="list-style-type: none"> The patient experiences symptoms such as: slight weight loss, fatigue, mouth ulcers, skin rashes and itching. Diseases include shingles and recurrent infections of the upper respiratory tract (mouth, sinuses, and throat). These symptoms and infections are categorised as minor and are not life-threatening. However, they may be unpleasant and debilitating. |
| Stage 3 | Symptomatic | Average period of five years | <ul style="list-style-type: none"> The patient is weaker and spends more time in bed. Symptoms such as high temperature, night sweats and diarrhoea that last for more than a month. Weight loss increases. The patient may have serious infections such as tuberculosis (TB) and pneumonia. Fungal infections of the mouth and genitalia are common (thrush). |
| Stage 4 – AIDS-sick | Advanced Disease | Average period of 5-13 months | <ul style="list-style-type: none"> This is the last stage of HIV infection when the patient is said to have developed Acquired Immune Deficiency Syndrome (AIDS). Syndrome refers to the collection of symptoms and diseases that characterise advanced HIV infection. By this stage the patient is very unwell, unable to care for his/herself and often bedridden for long periods. Weight loss is profound. The patient will have one or more serious infections or cancers that cause damage to the organs of the body and are potentially life-threatening. |
| OR | | | |
| Stage 5 (ASSA 2003) | HAART is initiated when the patients CD4 count is ≤ 200 cells/mm ³ | Survival depends on CD4 count and age at baseline | |

Source: Mendelson and Almeleh (2006); www.who.org.

illustrated by the narratives discussed in this paper, the social context affects the decision to disclose, but it is in turn, reconstituted by it.

Serovich (2001) compared two disclosure theories that focus on the impact of disease progression on the decision to disclose: the disease progression theory; and the competing consequences theory (see Figure 1). The disease progression theory provides a model of disclosure whereby the HIV-positive person discloses his or her HIV status when HIV progresses to AIDS thereby making it impossible to keep his or her status a secret any longer (Babcock, 1998 & Kalichman, 1995 cited in Serovich 2001). As shown by Table 1, the progression of HIV leads to a severely compromised health status characterised by visible signs of illness and hospitalisation. The competing consequence model assumes that there is no direct linear relationship between disease progression and disclosure. When sick, the person first weighs up the risks and benefits of disclosure (assesses the consequences) and then discloses accordingly.

Figure 1: Two theories of HIV disclosure



Source: Serovich (2001: 358).

The disease progression theory is arguably over-simplistic in the way it assumes very little volition on the part of the HIV-positive person. This theory assumes a causal relationship between health and disclosure, whereby a person will eventually be forced to disclose in order to gain necessary support or resources. There is no room for the person to decide to disclose before becoming sick with AIDS. The competing consequences model was found to be more flexible as it gives more volition on the part of PLWHA and can accommodate a wider range of disclosure experiences (*Ibid.*).

Table 2: Relevant details of study participants:

| <i>Name</i> | <i>Age*</i> | <i>Education (Grade)</i> | <i>Marital Status*</i> | <i>Age at HIV Diagnosis</i> | <i>Date of HIV Diagnosis</i> | <i>Motivation for seeking an HIV test</i> |
|--------------|-------------|--------------------------|------------------------|-----------------------------|------------------------------|---|
| Zameka | 23 | 9 | Married | 20 | Sep-00 | Pregnant |
| Dunyiswa | 24 | 11 | Single | 20 | Mar-00 | Pregnant |
| Liziwe | 33 | 8 | Single | 30 | May-00 | Sick |
| Nonceba | 27 | 11 | Single | 21 | Dec-98 | Baby diagnosed HIV+ |
| Nokwanda | 35 | 11 | Single (boyfriend) | 31 | Jul-00 | Sick |
| Ntombikayise | 33 | 12 | Single | 30 | Jun-01 | Sick |
| Ncumisa | 38 | 11 | Single | 34 | Mar-00 | Pregnant |
| Nondumiso | 29 | 12 | Single | 26 | Mar-01 | Sick |
| Lizeka | 26 | 12 | Married | 23 | Jan-01 | Pregnant |
| Zoliswa | 31 | 11 | Single (boyfriend) | 29 | Mar-01 | Sick |
| Buyiswa | 28 | 12 | Single | 26 | Sep-01 | Pregnant |

Note: * At time of interview January 2004.

In testing the two theories using 138 HIV-positive MSM, Serovich (2001) found that neither theory provided an adequate global understanding of disclosure. Rather, the theories may explain disclosure to family or friends, but not to sexual partners. Furthermore, neither theory provides any space for the social context to influence disclosure decisions, or for more altruistic motivations for disclosure – such as wanting to educate people about HIV and to change their social attitudes towards people living with HIV/AIDS. As shown in this study,

disclosure is both a response to, and in turn shapes, the social world of people living with HIV/AIDS.

“If you get sick, people will assume your positive status”: Community perceptions of HIV and health

You know when you are very sick, people are suspicious. Because now [as] an HIV-positive person you [are] sometimes becoming very sick, so people are suspecting that you may be or you must be positive. (Nokwanda)

If you get sick, people will assume your positive status even before you have tested for HIV. People might judge you as being HIV-positive because you look sick. (Buyiswa)

If you are lying on the bed and are sick, they [the community] understand. (Lizeka)

Nokwanda, Buyiswa and Lizeka (above) refer to their communities' understanding of illness and HIV. Another participant, Nonceba (below), highlights specific opportunistic infections common to stage three and stage four that may be mistaken for a positive HIV status.

As long as you have lost weight and you dropped your weight down, then they will say “Phew, she’s HIV-positive”. (Nonceba)

Nonceba (who has since begun ARV therapy) adds that stigmatising attitudes were expressed by her community because she ‘looked’ like she was infected with HIV. However, she was not yet diagnosed HIV-positive.

... Like they saw me walking on the streets, they will say, “There is that bitch that has got AIDS.” So, all those things, they are not good to hear. Like before I know my status while I was very, very sick, so they were always saying that that lady has AIDS. But now that I am well, I am fine; they don’t have those words again. (Nonceba)

Although she had begun HAART and her health had improved, the scarring left by skin rashes were a constant possible identifier of her positive HIV status.

Like I had those sores on my face, so even while ... I was taking the treatment in Site C, while I was passing [over] the road from home to

the Cite C clinic, I used to pass next to the [taxi] rank, so the taxi driver used to just come and look at me, “Oh, you can just see from her face that she has AIDS.” (Nonceba)

In the focus group discussion, Liziwe added the following about ‘looking HIV-positive’ to the rest of the groups’ amusement:

What Liziwe is saying is that her community knows that she is HIV, because she disclosed to them....but because now she is well they don’t believe anymore. So she doesn’t understand why [the community thinks that] someone with HIV must have horns or... look different. (Liziwe translated by Buyiswa)

There are numerous references to bodily illness as a signifier of HIV infection in the women’s narratives, and many other people living with HIV make similar suggestions along these lines. When they are physically and visually sick, it is assumed that they are HIV-positive.

On the other hand, Ncumisa has known her HIV-positive status for 5 years, but her immune system has coped extremely well and she has not experienced severe opportunistic infections. Ncumisa’s experience of disclosure to her immediate family in the Eastern Cape is a poignant description of the perception that HIV is recognisable in the popular imagination. She disclosed to her brother nine months after she was diagnosed as she was confident that he would give her support. Her brother was understanding and supportive as he was also HIV-positive. It was more than two years later when she disclosed to the rest of her family. She was not sure what their reaction would be because she heard one of her sisters speak negatively about PLWHA. She decided to disclose to her immediate family when she went back to the Eastern Cape for the holidays.

One afternoon, after slaughtering a cow, all the women were sitting inside the house, when her sister told her about another woman who had disclosed her HIV-status to her family. Ncumisa’s sister then asked her about her job that she knew involved HIV/AIDS.⁴ She then called all her siblings and her mother together and told them that she would tell them something and then tell them more about her work. She told them her whole story, from when she was diagnosed HIV-positive while pregnant, and took AZT so she would not infect her child, to when she began facilitating Memory Box workshops and her involvement in support groups. Her family did not believe her and thought she

⁴ At the time of the interview, Ncumisa was facilitating peer-education and psychosocial support workshops in support groups for PLWHA in clinics and for NGOs. These workshops were run by the Memory Box Project and were based on a combination of art and narrative therapy.

was lying. She had given her sister the *Longlife* book, but her sister had not realised that it was her story inside the book.

And then my sister looked at me and also my mother looked at me. They say you so fat but you say you HIV-positive. I said, “Don’t point fingers ... You can be thin because of stress ... HIV-positive people [are] not thin.” If I tell the people here in the Eastern Cape I am HIV-positive, they won’t believe me. (Ncumisa 2004)

Her sister and her mother did not believe that she was HIV-positive as she was looking very healthy. They asked her if they could phone somebody to confirm that she was indeed HIV-positive. Ncumisa phoned Jonathan Morgan (then director of the Memory Box Project), who called them back and confirmed her HIV status. They still did not believe. Ncumisa knew of another woman who worked for Wolanani, an income-generation project for PLWHA in Cape Town, who was in the Eastern Cape at the time, and she asked her to come to her family’s home to tell them about her HIV status. It was only after this woman came to visit Ncumisa’s family that they finally believed that she was indeed HIV-positive.

Another woman, Lizeka, also tells of disbelief when she disclosed her status to her mother.

... she didn’t understand, [s]he didn’t believe ... because she said, “No you are lying. People who have got AIDS [are] sick.” (Lizeka 2004)

From a different perspective, the data suggests that some people may be confused about their own HIV status due to the community’s reaction to them after they disclose. Buyiswa said that if she did not have adequate HIV knowledge, she would doubt her own HIV-positive status.

If I am not in my house, [or] they don’t see me for two days, they will come and like people who like support me in my community always come to see if I am sick or something. Some of them say, “No, [we never] see you really being sick. And your children are healthy. Why do you think you have HIV? Because what if the test was wrong.” Because of that, if I did not have enough information about HIV, I will doubt my status because people will really make you doubt if you are really HIV-positive, because of the things that they say when you are not sick. (Buyiswa 2004)

Zoliswa summed up the confusion surrounding the manifestations of HIV/AIDS when she spoke about the importance of public disclosure and knowledge of the ARV treatment programme.

It's important to do that, to disclose to the community. Because maybe ... my community ... saw I was sick, then they saw me while I was putting [on] weight. They are confused. "What is going on [with] Zoliswa, because we don't know now before?" Maybe before they say ... that "I think she is HIV". But then they saw me [putting on] weight. Say, "Ooh I don't know what is going on?" So the community they must know, you can get sick, but there is something that can help you ... and your life is coming back again. (Zoliswa)

However, community perceptions of HIV/AIDS are not exclusively innocent misunderstandings of the aetiology of HIV/AIDS, but include more malicious attitudes towards people living with HIV/AIDS, especially women. Within this context, people fear being identified as being HIV-positive.

According to the majority of the participants' narratives, the overriding apprehension of being identified as HIV-positive is largely based on fears of 'gossip' (Almeleh 2004). Gossip seems to be the most common and hurtful form of discriminatory attitudes experienced by the participants within the community context. Participants retell experiences where they hear that they are labelled as promiscuous, prostitutes, witches or "loose" women, especially when they are identified as or assumed to be HIV-positive when they are visibly ill.

On my side, to my community, I won't disclose to them. Because the other day when I was at home sitting with my child and my child was very young and then they ask me. The other lady was *lustig* [curious]. My neighbour asked me why I didn't breastfeed my child. I just told her I have got a problem to my breast. So she just spread it to the other people, why I am not breastfeeding my child. When I found out she was talking bad about me, I told myself I am not going to tell the community about myself. And the other thing, they are always asking me why I have got the formula milk, and "where do I get the formula milk because I am not working and also my boyfriend is not looking after me?" So I told myself, where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can say bad things outside about you. (Ncumisa)

Ncumisa explains further:

Because if you walk, come out of your gate and you walk out in the street, you see the people making some funny jokes. So that thing can hurt you because you disclosed to them now they got stigma on you now. (Ncumisa)

Nondumiso expressed similar sentiments, although she refers specifically to her African community.

But if you come to the black community, if the people that know you, gossip and jealousy and like getting you down, you know. They not like giving you support, you understand. (Nondumiso)

The other reason why it is hard to disclose to the community ...Maybe you will decide to disclose to the neighbours.... There are big mamas there that know your mama. They gossip ... they are witches; they practice witchcraft and all this things.. And you just go and say this, I am HIV-positive ...They say bad things and all things like you are sleeping around. (Nondumiso)

In a study done in KTC, a low-income township in close proximity to Khayelitsha, Mills found similar instances of ‘gossip’ and blame. People who were identified as being HIV-positive were said to have “too much sex”, “too many boyfriends or girlfriends” or told they were promiscuous and unfaithful (Mills 2004:8). France (2004) also describes such gendered moralistic judgments in her research on the causes and experiences of stigma in Africa. She refers to the quotes below as representative of a common problem in all the countries.

In almost all interviews, women were cited as suffering more from stigma – “they are blamed for the spread of HIV by their partners and families which is related to notions of promiscuity. Women suffer because they come out whereas men hide their status and blame women”. “If a woman is HIV+, she is blamed for infecting the man. If the man is sick it is seen as an unfortunate stroke of luck – he is given sympathy and not blamed”⁵. (France 2004:3)

These experiences, as well as those documented in many other studies clearly demonstrate the link between experiences of stigma and discrimination and the gendered nature of HIV/AIDS in sub-Saharan Africa (LeClerc-Madlala 2001). Women are seen as one of the vectors of HIV transmission, as well as having responsibility over contraception, carrying the burden of care, being

⁵ France (2001) quotes focus group discussions with religious leaders in Botswana/Namibia in March (2001), and in Tanga, rural Tanzania, April (2001).

economically productive and maintaining the household. Women are also tested more frequently than men (in antenatal care), and are more often knowledgeable of their HIV status than men. As a result, women are in the position to disclose more often than men, and therefore may be seen to be bringing HIV into relationships. Men seldom visit Voluntary Counselling and Testing (VCT) sites and do not know their HIV status until they are in the final stages of HIV infection or are forced to do so. They therefore are not often in a position to disclose as they do not know their HIV-status. Under these circumstances, they are rarely blamed for bringing HIV into relationships, and are rarely the recipients of malicious gossip. However, beyond these structural constraints, and from a socio-cultural perspective, even if men did disclose first, women may still be blamed for bringing the virus into the relationship.

Cultural processes

In his book *Witchcraft, Violence and Democracy in South Africa*⁶, Ashforth discusses the associations between HIV/AIDS with witchcraft by arguing that common symptoms of AIDS, such as persistent coughing, diarrhoea, abdominal pains and wasting ‘have long been associated in this part of the world with the malicious assaults of witches’ (2005: 9). In his section on the ‘sociology of jealousy’ Ashforth highlights gender differences with regards to conflict and sheds some light on the gendered nature of blaming in the context of HIV/AIDS. He argues that, in general, men (in Soweto) are more likely to use violence in conflicts, while women are more likely to resort (or be seen to be resorting) to witchcraft – especially conflicts that involve jealousy (*ibid*: 74). These conflicts typically happen in relationships that are more prone to jealousy, such as in relationships between spouses and lovers. He cites the following example: “When a man dies, his wife will automatically be suspected of killing him. The motive again will be jealousy” (*ibid*: 74).

The story of Fana Khaba adds substance to the idea that women are automatically blamed for misfortune, including HIV/AIDS. In the book *Khabzela*, McGregor tells the story of Fana Khaba (DJ Khabzela), a popular Johannesburg Radio DJ who rejected HAART and died of AIDS after an unsuccessful search for alternative therapies. Khaba rejected conventional HAART treatment, and instead, he relied on alternative healers that promoted therapies such as: ‘Dr Irene’ and her ‘Amazing Grace’ pills, and Tina van der Mass and her ‘Africa’s Solution’ treatment⁷ (McGregor 2005). Khaba’s body wasted away and he died because his immune system was unable to recover

⁶ The focus of the book is Soweto (in the province of Gauteng, South Africa).

⁷ McGregor reports that the Minister of Health, Manto Tshabalala-Msimang, phoned Khaba’s mother in October 2003 to tell her that she was sending Tine van der Maas to help them.

with these alternative therapies. Khaba's fiancé, Sibongile, described to McGregor how she was blamed for the death of Khaba. In Khaba's story, his affliction with AIDS was blamed on witchcraft, which inevitably placed the blame of women.

Interestingly, Ashforth argues that witchcraft and gossip are inextricably linked and one cannot be understood without the other. In terms of the current study, there are clear links between disclosure, stigma, illness, jealousy, witchcraft and gossip. According to Gluckman (1963), gossip is an integral part of all aspects of community life, and has the ability to unite the community or set it against a particular group. Nondumiso, for example, blames the stigmatising gossip on the witches in her community, while many of the other women blame the stigmatising gossip on other experiences, including contexts when they were seen collecting social grants, food parcels and formula feed for their babies. The experiences of the 'gossiping witches' illustrates Gluckman's analysis. The "big mamas" who are gossiping are uniting themselves against HIV-positive people, using gossip to divide the "us" from the "them" – similarly to the common "us" versus "them" explanation of AIDS-related stigma (Joffe 1999). Interestingly, Nondumiso speaks of the gossipers as witches, which ties in to Ashforth's description of the importance and function of gossip.

"Gossip is the primary medium within which invidious comparisons are made between members of social networks and within which sexual indiscretions are revealed. These comparisons and revelations feed the secret envy and jealousy that are the motive forces of witchcraft" (Ashforth, 2005: 67).

Historically, HIV/AIDS has been linked with sin, sex, shame, death and deviance. Similarly, witchcraft has been linked with shame, sex, death, illness, deviance and gossip. Further questions need to be asked about why PLWHA fear gossip so much. Are their fears of gossip linked to fears of witchcraft, and to what extent do they perceive witchcraft to be the source of their illness and misfortune?

Avoiding stigmatising attitudes (characterised by blame and gossip) in the community, while simultaneously accessing treatment, care and support is the tricky path PLWHA aim to negotiate. However, this can be especially difficult when PLWHA get tested in the latter stages of the disease and are already experiencing serious opportunistic infections. Once again, HIV/AIDS is reinforced as a hidden, mysterious and importantly, an exclusively debilitating disease. In this sense, the life experiences of PLWHA are bounded by their social context and their individual actions are a response to their environments, which reinforce and reproduce popular perceptions about HIV/AIDS.

How do individual experiences interplay with social forces?

The participants of this study encountered VCT when they were either pregnant or sick (see Table 1). In Tanzania, Maman *et al* (2001) also found that women's decisions to access VCT were motivated by their reproductive health problems (pregnancy), own sickness, or the sickness or death of a child or partner. In the most recent South African study of HIV prevalence a significant percentage of respondents used VCT services because they were pregnant or they were sick (Shisana *et al* 2005:83). In terms of disclosure, Norman *et al*'s (2005) research in two different South African communities found that most of their respondents disclosed in order to access support, specifically emotional and health-related support. Importantly, disclosure was a catalyst for accessing support (*Ibid.*).

Because people are getting tested when they are sick or pregnant and only disclosing in the latter stages of HIV-disease, HIV/AIDS may be perceived as an illness that begins with a seriously compromised health-status and ends with death, unless HAART is introduced. The first two stages, in which only slight or mild symptoms are experienced, do not seem to influence the perception that good health is possible when somebody is HIV-positive.

The current study supports such a hypothesis. Approximately half of the study participants were diagnosed when they were sick (stage 4 or AIDS sick) and disclosed soon after due to their compromised health status and a need for health-related social support. Those that were diagnosed while pregnant and healthy took far longer to disclose and disclosed to less people. Because a large percentage of the women disclosed while seriously ill, their significant others perceived HIV/AIDS to be synonymous with visible infections such as skin rashes, TB, weight-loss etc.

If HIV-positive people disclose while healthy, popular perceptions may be different. However, this situation seems unlikely due to perceptions and fears of stigma and discrimination. Such individuals are not yet visibly sick, yet they fear possible stigmatisation if they are identified as HIV-positive (Alonzo and Reynolds 1995). Loewenson and Whiteside (1997) argue that a key characteristic of HIV/AIDS is that the person may live a normal productive life for many years before and after he or she is diagnosed. HIV-positive people in this position are therefore able to spend a considerable period of time deciding whether to get tested, or whether to disclose if they already know their status. If the person is not willing to risk possible discrimination, he or she will probably not disclose and will not access social support related to their HIV-positive status. As the individual progresses to the more serious symptomatic and visible

phases, such non-disclosure means that he or she is not accessing appropriate levels of care.

The timing of diagnosis is a critical factor in the disclosure process. People learn of their status at different points on the biophysical HIV trajectory which inevitably affects the ways in which they are able to deal with a positive diagnosis. For example, if the person is visibly sick with weight-loss, TB or skin rashes, yet has not disclosed, he or she may be assumed HIV-positive as in the cases of Nonceba, Nokwanda, Zoliswa and Liziwe. In a study of lay health beliefs regarding HIV/AIDS in East Africa, Nicol *et al* (1993) found that people thought they were able to recognise an HIV-infected person by observing his or her weight. This was attributed to the fact that wasting syndrome is an opportunistic disease associated with being AIDS-sick, so when people are fat, it is assumed that they are not HIV-positive. On the other hand, the current study shows that if the person is well (stage 1 or stage 2, and asymptomatic) when they are diagnosed and disclose during a phase of good health, people questioned their HIV-positive diagnoses, as in the cases of Ncumisa and Buyiswa. It thus appears that if you are healthy and HIV-positive the community may not believe you, and if you are visibly sick and/or identified as HIV-positive, you may be gossiped about by people in the community.

What are the motivations for disclosure?

The qualitative data suggest two key motivations for disclosure; to access health-related social support (individually-focussed), and to educate others about the realities of HIV/AIDS (socially-focussed). Furthermore, the data shows the complexity of the disclosure process, where additional motivations interplay with the primary motivations. They include: maintaining control over treatment and care requirements; attempts to improve and maintain psychological well-being; sustaining and nurturing significant relationships; and countering prevailing misconceptions around the relationship between HIV/AIDS and health.

Table 3: Context and Motivation of Initial Disclosure to Significant Others

| Name | Motivation for seeking an HIV test | Health Status at 1 st Disclosure | Time between diagnosis and disclosure | Motivation to Disclose | |
|--------------|------------------------------------|---|---------------------------------------|---|--|
| | | | | Think about the first time you disclosed: | |
| | | | | Who did you disclose to? | Why did you disclose? (quotes from self-administered questionnaire) |
| Zameka | Pregnant | Healthy | Approx. 2 years | Mother | “She had a problem with her partner; he had sexual transmitted disease, so advice her to go for a test, she was afraid, so I told her she is going to be fine because I am also HIV-positive.” |
| Dunyiswa | Pregnant | Healthy | Approx. 2 years | Boyfriend | “He used to badmouth people living with HIV, so I hated that, so I decided to disclose to him.” |
| Liziwe | Sick | Sick | 0 years | Sister | “She was my caregiver” |
| Nonceba | Baby diagnosed HIV+ | Sick | 3 years | Mother | “I was going to start ARV treatment and I needed an assistant and I was staying with her.” |
| Nokwanda | Sick | Sick | 0 years | Mother and cousin-sister | “I disclosed because the illness was not getting better, and my mother was going up and down trying to seek for help” |
| Ntombikayise | Sick | Sick | 0 years | Mother | “I knew that I was going to die so I wanted to tell her before I die” |
| Ncumisa | Pregnant | Healthy | 9 months | Brother | “Because I wanted support from one of my family member knows about my health” |
| Nondumiso | Sick | Sick | 0 years | Brother | “Closest person to me” |
| Lizeka | Pregnant | Healthy | 9 months | Boyfriend | “Because I wanted him to be carefully about the HIV and get tested and use condom always” |
| Zoliswa | Sick | Sick | 0 years | Brother and Sister | “I was sick. I had TB.” |
| Buyiswa | Pregnant | Healthy | 0 years | Friend then mother | “I disclosed a few hours after I was diagnosed. It was just something I wanted to do.” |

Disclosure recipients

Table 3 lists participant data relevant to the disclosure process. Six of the eleven participants disclosed during the symptomatic phases of HIV/AIDS, while five were asymptomatic at the time. The most common disclosure recipient was the HIV-positive person’s mother. Other disclosure recipients include (in order of frequency); brothers, sisters, boyfriends, cousin-sisters and friends. The following excerpts from the in-depth interviews shed light on the process of disclosure and the relevant motivations to these significant others.

Setting the scene

The timing of the disclosure was very important for many of the women. This may be due to fears of stigma and discrimination, and the potential relational risk of disclosure. Some of the women had to wait until they had ‘accepted’ their status and were ready to tell others, while others needed to either test what reaction they would get when they disclosed by bringing up HIV/AIDS in conversation or displaying HIV/AIDS-related materials. Timing was also affected by the time taken to select the correct person and to analyse the potential consequences of the disclosure.

But for me I always say ... you cannot say I am going to disclose and such and such a thing, you have to be ready. As a person and you have to be, you have to know what you will be dealing with after you have disclosed. So I cannot say when is the right time to disclose. I always tell everybody that it has to be within you. But it is important that one member of your family, more especially, not the public, knows your status because at the end of the day you will definitely need the support from your family and from friends, because mostly what is important is for you to get support from people that really care about you. (Buyiswa)

Buyiswa is adamant about disclosing for the correct reasons and to the correct people, and she realises that who the ‘correct’ person is will vary from individual to individual. Buyiswa’s opinion is interesting as she has never been seriously ill due to HIV, yet she realises the need for social support from people that care for her. Nondumiso describes the questions that she asked herself before she disclosed.

Okay disclosure for me I will say, other people will find it difficult. First of all you must...know what kind of person you gonna disclose to. Is this person important to you? Is it important for you to disclose to this person? Why are you disclosing to this person, the reasons why you are disclosing, you know. Then after that if the person reacts in a different way, how are you going to handle the person, you know? You going to talk to this person and maybe educate and let the person know, what are your weaknesses, what are your fears about disclosure, so that the person understands. And the situation where you disclose it can be different. Also you must also first think about the person, how the person is going to feel. You must not only think about how you are going to feel. Also the person you knowing how the person is feeling. (Nondumiso)

Nondumiso thought very carefully about the disclosure process. Apart from disclosure for personal gain, she was also worried about the feelings of the disclosure recipient considering they were a loved one and the relationship was important to her.

As mentioned previously, the timing of the disclosure is an important part of the process. In some cases this is due to the person wanting to test whether the person they will disclose to is ready to receive their disclosure information. For Nondumiso (above) it was about testing how the person would feel, while Ncumisa (below) waited until her family members displayed more acceptance towards PLWHA.

The way they were talking, I thought they [needed to] change their attitude. Because when I visited them, it was on Sunday afternoon when I go to them and visit them. One of my sisters tried to talk bad about people living with this virus. So I told myself I am not going to disclose my, I will wait till I get the time to disclose to them. (Ncumisa)

Similarly to Nondumiso and Buyiswa, Ncumisa also feels that she needed to have accepted her HIV status before disclosure in order to be emotionally prepared for the potential consequences. Lizeka (below) also had to go through a process of coming to terms with her HIV-positive diagnosis, as is the case with many of the women. However, when she had finally decided to disclose, she tested her friends and family's reaction by leaving the *Longlife* book with them, in order to gauge their reaction, and in a way, disclose through the book.

Before I disclosed to my friends in J-section in my community, I was hiding too. What are you going to start with you know? But I took the book, the *Longlife* book, and I put it in a room and then they I go to the bathroom and I go to wash and then they came there and then they see that, they saw that book and they read it and they ask me, "Lizeka, what is this about?" I told them "You read in that book what is written there, so it's the truth." So they told me, the other one, she told me that "Me too I am HIV-positive, so we are friends and we are the family." So they supported me, no problem. (Lizeka)

Lizeka employed a different strategy where she disclosed through the *Longlife* book as opposed to a one-on-one conversation. Importantly, others have also used this strategy to disclose. In general, it is important to note that different people have different disclosure strategies, yet common themes can be identified such as waiting for the most appropriate moment.

Disclosing due to health-related concerns

Although setting the scene for disclosure was very important, and many of the women waited some time before disclosing, the need for social support due to health concerns, to some extent, ‘forced’ some of the women to disclose. In the context of disclosing out of health-related concerns, Nokwanda’s first response to the disclosure issue is in line with many of the other women’s responses. Nokwanda was tested positive in July 2000, and disclosed her status to her mother in October 2000. She disclosed to her mother because she was experiencing serious opportunistic infections and was not getting better, and her mother was providing care and support. Nokwanda felt a responsibility to disclose to her mother because her mother was trying to help her and she needed the correct treatment. Although she was sick, she found it difficult to disclose. Her views on illness and disclosure echo with most of the group.

In 2001, Zoliswa was diagnosed HIV-positive. At first, Zoliswa hid her status as she was not ready for possible negative reactions. She felt less fearful of her family than her friends. She told her family quite soon after her diagnosis as she explained that she was sick with TB at that time.

Nondumiso disclosed to her family very soon after her diagnosis. She connects her visible signs of illness (skin rash) to having no choice but to disclose.

It’s because of my skin problem. That is the reason that is making me ... disclose. Because they are going to ask me: “What happened to your skin, why is your skin like this and all that.” I have to lie, its not good lying. I am going to tell the truth. So that is one of the reasons that makes me disclose ... Otherwise maybe if I didn’t have a skin problem, I wouldn’t be disclosing. (Nondumiso)

Liziwe reached a stage where her health was compromised to the degree that she was unable to do normal daily activities.

She said she was very sick, she couldn’t bath herself, she couldn’t walk, she needed somebody to feed her, she couldn’t do anything, so that’s why she decided to disclose so that the people they can help her and they can give their support. (Liziwe, 2003 translated by Ncumisa)

In Nonceba’s case, although she had negative experiences in her community, she wanted to disclose to her significant others. She too was experiencing serious opportunistic infections and required appropriate support. HIV is different to other diseases and she realised that it was necessary that the person looking after her needed to know exactly “where to go and what to do”. She

feared that the incorrect treatment would lead to a further compromise in her already compromised health status.

Nonceba and Nondumiso share similar experiences with many of the other participants. Their decision to disclose was at first bounded by fear of stigma. The fear was overcome by a need to engage with their significant others in order to deal with the biophysical nature of HIV disease. All of these women carefully selected their disclosure recipients, and in all cases, their disclosures were received positively by family members, and support and care continued.

Maintaining control over treatment options

The relevance of disclosing out of personal health concerns is not limited to seeking health-related support, but to the particular treatment and care required. Both Ntombikayise and Zoliswa feared being sent to a traditional healer if they became ill. Ntombikayise connects her fear to disclosure, that is, if you do not disclose, you will be taken to the traditional healer and people experience further illness if they ingest the treatment prescribed by the traditional healer.

But if you are sad, you won't tell the people what's wrong with you. Us black people, we believe in the *sangomas*. Sometimes the people take you to the *sangomas* and they make it [HIV] worse, because the medicine, the herbs or the *sangoma*, they are very strong for us. (Ntombikayise)

Zoliswa and Dunyiswa agree with Ntombikayise's lack of trust in traditional medicine and place importance on getting the correct treatment for HIV. It is important to note that all of these women have been on treatment literacy courses facilitated by the Treatment Action Campaign⁸ (Almeleh 2004).

... So I don't want my family to take me to the traditional healers ... Maybe the traditional healer gives you strong medicine and then you become weaker and weaker and weaker, and end up dying. (Zoliswa)

The decision to disclose is carefully managed and timed by the individual in order to maintain control over their treatment and care options, and hence receive specifically selected forms of support. In Zoliswa and Ntombikayise's cases, they were motivated to disclose as they did not want to be taken to traditional healers, but rather to their clinic doctors.

⁸ See Ashforth and Natrass (2006).

The interplay between the western biomedical paradigm and the alternate traditional medical paradigm is interesting and complex. Data from the Khayelitsha Select Panel Survey (Wave 1 – 2004) shows that 16% of respondents claimed to have been to either one or more *sangomas* prior to starting ARV treatment. Of those 40 respondents, only two visited traditional healers after starting ARV treatment. Patients who begin ARV treatment undergo intensive HIV/AIDS education and treatment literacy prior to beginning treatment. Similarly, all the participants in the current study have high levels of education around the transmission and management of HIV through organisations such as Medecins Sans Frontiers, TAC, Mothers to Mothers, and ASRU. This education is strongly based within the biomedical paradigm (Ashforth and Natrass 2006). Anecdotal evidence suggests that the use of traditional medicine is discouraged by educators and health professionals. This point is evident from the *Longlife* book where Dunyiswa states:

I think if you are going to take traditional medicines you need to talk to your doctor about them, but because MSF emphasise ARVs, that cause us to keep quiet about what we are doing with traditional medicines. (Morgan and the BWG 2003:72).

Biomedicine has proven success for every member of the group, because they have either seen their own health improve dramatically due to HAART or have been through Prevention of Mother to Child Transmission (PMTCT) and their babies have subsequently been born HIV-negative.

Accepting advice from health professionals

Disclosure in times of ill health is not only a necessary choice of the person living with HIV, but also a recommended decision from the health-care perspective. Nonceba and Nokwanda describe their experiences with health-care workers:

The nurse was told me: “Disclose to your mother or one member in your family”. I said, “No.” She said to me, “You must disclose maybe to one. You must choose the right person then you must disclose. Then if you are sick, they can take you to the hospital.” (Nonceba)

My cousin-sister for example, she’s the nursing sister here in Jooste Hospital. She just took me to MSF. I didn’t know anything about MSF. So the minute I told her that I am HIV-positive, I am diagnosed HIV-positive, and she went to find help for me ... I can say that our

relationship was [better] when she heard that I am HIV-positive, than before. (Nokwanda)

It is common for health-care workers to encourage disclosure. This is evident through the National ARV Treatment Guidelines, in which, under psychosocial criteria for starting HAART, it states that it is “strongly recommended that clients have disclosed their HIV status to at least one friend or family member” (Department of Health 2004). Health-care workers realise that appropriate social support (specifically related to the HIV condition) is unlikely in the absence of disclosure to those that can give support.

The situation of HIV-positive people has changed somewhat with the introduction of a universal roll-out of HAART. HAART patients only receive treatment when their CD4 cell counts are less than 200/mm³, that is, when they are clinically AIDS-sick and already experiencing the opportunistic infections (Department of Health 2004). The introduction of HAART adds an important dynamic to the disclosure situation. The patient’s health on HAART increases dramatically over the first six months of treatment, with fewer opportunistic infections experienced (MSF *et al* 2003; Coetzee 2005). Importantly, patient’s perceptions of their health tracks improving clinical health markers (Coetzee 2005). Therefore, disclosure gradually becomes easier due to the psychological and physiological benefits of HAART (Klitzman *et al* 2004).

From a social support perspective, during the first few months on HAART, health-care professionals in the clinic setting as well as community-based health-care workers provide intensive and continuous support for all patients on HAART. Patients are asked to identify ‘treatment buddies’, next of kin, and are directed towards community organisations that can contribute or support household, food, financial and social security. Patients’ support networks therefore increase outside the household context, which makes it easier to engage with close household members for support.

Nurturing existing relationships

Of all of the participants in this study, none discuss negative experiences of disclosure to their chosen household members. In the majority of cases where disclosure took place during a severely compromised health status, the support and care continued. Even when disclosure took place when the person was asymptomatic, the participants’ significant others were encouraged to engage with the HIV/AIDS issue, learn more about it, and administer the care that was necessary to ensure the well-being of their loved ones.

The nature of relationships, with kin, household members and friends, is based on reciprocal obligations between parties. 'Trust' is an essential part of these obligations. After being looked after for so long by these significant others, the women felt a responsibility to tell them about their HIV status.

Because they are the people that are close to me and they are the ones who were looking after me while I was sick, even though now they see that I am healthy. They need to know about what is happening and what has happened. (Nonceba 2004)

Another woman, Ntombikayise, felt that the disclosure message ought to come from her. It would possibly be harmful to the relationship if her significant others found out about her HIV status through a third party. According to Communication Privacy Management theory, hearing of their HIV-positive status from a third party would cause 'boundary turbulence', that is, where privacy boundaries are breached without the consent of the person whose secret is being betrayed (Greene *et al* 2003; Petronio 2002).

I don't care about the community, but I feel I will not be alright when I [don't] tell you and then somebody [else] says, "Oh Ntombikayise you are HIV-positive. [X] told me." I will not feel alright. (Ntombikayise)

For Ncumisa, she did not want to be treated differently.

...they make me very upset and they always buy everything at home for me. I say, "No guys, what you are going to eat, I am going to eat. I am not a separate person who must eat this and who mustn't eat that. I eat everything but I must limit myself from the other things, like alcohol, like sweet things. All those things I mustn't eat. (Ncumisa 2004)

She stressed the fact that her relationships with her significant others should remain the same although she was HIV-positive. Her disclosure was also an opportunity for her to educate her significant others about the needs of HIV-positive people.

Educating others

Educating significant others is an important reason for disclosure amongst a number of the research participants. This is especially the case amongst those participants who had never experienced serious opportunistic infections and who were diagnosed while pregnant. This may be attributed to the fact that they are

activists, wanting to change popular misunderstanding of HIV/AIDS in Khayelitsha, or wanting to protect their loved ones from possible infection. However, it is plausible to assume that because of their HIV infection and experiences of HAART or PMTCT the women are 'experts' and therefore can protect their loved-ones through education based on real life experience. Lizeka and Zameka disclosed to particular family members due to such concerns.

Lizeka disclosed to her younger brother as she wanted to educate him regarding prevention. This method of disclosure was also a method of testing her brother's reaction to issues surrounding HIV/AIDS.

So I educate my brother, my youngest brother. He is 22. I educate him first ... Firstly, I teach him about the condom, he must use condom every time because there is a virus outside ... He understood, and another time I asked him: "If I told you that I am HIV-positive, what will you do?" He said, "Oh, no problem because you are my sister. I can help you if maybe you need money, maybe to buy some medicines, or if you are sick I can hire the transport to go with you to the clinic, I don't have a problem." ... And then I told him that I am HIV-positive. He was crying a lot, but he told me, "No problem. I am here for you, no problem. If you have a problem, tell me. I am going to help you. I am working, no problem, we are together now, don't be stressed about this because you are HIV, its all over the world." (Lizeka)

When Zameka found out that her father was having multiple sexual partners, she felt the need to educate her mother so that she would take the necessary precaution. Dunyiswa disclosed to her ex-boyfriend so that she could challenge his negative perceptions of PLWHA.

He used to badmouth people living with HIV, so I hated that, so I decided to disclose to him. (Dunyiswa)

Dunyiswa's disclosure was not so much about providing facts about HIV/AIDS, but more along the lines of challenging his attitude towards HIV/AIDS. It was extremely brave of her to do so, considering the risk of knowing he had these negative perceptions. It seems that she felt the need to challenge his negative perceptions by locating herself amongst them, that is, how could he stigmatise other PLWHA when he was in love with someone who was HIV-positive and accepted her? Dunyiswa went on to say that this man left her after finding out her HIV-status, and blamed her for bringing HIV into their relationship.

Although Dunyiswa had not disclosed to her siblings, she expressed the desire to do so in order that they can learn from her.

All I want, I want to help my family. I don't want to my sister or my brother to be HIV-positive. (Dunyiswa)

Disclosing to your family is seen to be preventative in that you can educate them and serve as a role model for discouraging them from contracting the virus. In these situations, the women are empowered by their 'expert' knowledge of HIV/AIDS. Educating loved ones about prevention and HIV/AIDS in general is an important contribution that the women can make towards their families, within other important non-family relationships and towards changing popular misunderstandings of HIV/AIDS in their communities.

Maintaining psychological well-being

For many women, in the time following their diagnosis, they felt unable to disclose not only because they feared that they would not be accepted in the community, but also because they were struggling themselves to come to terms with being HIV-positive. Some of the women talked about a process of coming to accept themselves and their status. This process transformed the way they felt about being HIV-positive which led them to feeling increasingly able to disclose. While some of the women remain undisclosed, others said that they began to 'feel free' to disclose openly. In fact, many of the women drew on this notion of 'being' or 'feeling free' with their status as an important indicator of having overcome many distressing aspects of their diagnosis. For these women disclosing meant 'to be free' – free of fear and guilt – and they felt that by sharing the secret of their status, they no longer needed be burdened by it.

...the meaning of disclosure for me is to take out the thing that is inside of your heart and to tell another person, yes. The feeling of that is I can say it's a medicine for myself because when I talk to someone it's like I drink some medicine and get cured, yes. (Zoliswa 2004)

Because sometimes if you didn't disclose and you have a lot of stress and you thinking you alone in that time. So if you disclose to someone, you share your problem. (Lizeka)

Ncumisa discussed the long period of time between her diagnosis and the disclosure to some of her significant others. She thought that her disclosing would put too much stress on her household, specifically her aging mother. However, she did tell her family in the Eastern Cape (including her mother) four years after her diagnosis. She describes this as a very positive experience.

It feels better because you know that the pain, the pain is gone now ... Something like you are carrying a sick baby, you don't know when it's going to get better. But when you found out you did disclose that baby is feeling better now, it's alright like the other babies. (Ncumisa 2004)

This explanation is particularly poignant as a few years ago Ncumisa lost a young child. Interestingly, she articulates her newer, less stressful position, using a health metaphor. The health metaphor is common to many of the women's responses. They speak about disclosure as a form of medicine - the secret to curing the 'sick baby'. For some women in this group, anti-retrovirals are a treatment for the HIV-infected body, while disclosure is a treatment for the HIV-infected mind.

The degree to which people cope with the physical and psychosocial aspects of living with HIV/AIDS is to a large extent affected by disclosure decisions (Greene *et al* 2003; Schmidt and Goggin 2002; Holt *et al*, 1998; Petrak *et al* 2001). Poor emotional well-being, including depression and HIV-related anxiety, has been attributed to lack of satisfaction of social support due to non-disclosure (Petrak *et al* 2001; Armistead *et al*, 1999). Numerous studies have demonstrated the positive psychological benefits of disclosure, where revealing secret information to significant others is at first stressful, but consequently cathartic (Brandt, 2005; Petronio 2002; Greene *et al* 2003; Armistead *et al* 1999).

Discussion

The aim of this section is to highlight the important contexts and motivations for disclosure to significant others. The results show the complexity, contradictions and rationality of disclosure motivations. Two key motivations were identified: disclosure in order to access health-related support; and disclosure in order to educate others. It is important to note that all motivations occurred within specific relational contexts and were mediated according to the dynamics of these relationships.

The study participants were highly selective in their choices of who would receive knowledge of their positive HIV diagnoses. This is consistent with other international studies, where immediate family members were usually the first people to receive HIV diagnosis information (Kahn 2004; O'Brien *et al* 2003; Chandra *et al* 2003; Greene and Serovich 1996; Schmidt and Goggin 2002). Kahn (2004) found similar motivations for disclosure in her qualitative study of disclosure in another low-income area near Cape Town. Her research

participants strongly advocated disclosure within the household context as a means of mobilising support (*Ibid.*). In the current study, females (mothers and sisters) were the most frequent disclosure recipients (see Armistead *et al* 1999) followed by siblings, other family members, partners and friends. After mothers, disclosure recipients included significant others of both genders. Out of the six cases where disclosure took place during ill-health, five of the disclosure recipients included either mothers or sisters. The data suggests that females are the providers of health-related social support, while other family members provide much needed additional psycho-social support (especially when disclosure occurred while healthy). The gendered nature of disclosure recipients may also be attributed to the fact that all the research participants were women and would therefore choose other females for support (*Ibid.*).

For many PLWHA, disclosure is the means to access health-related support and services to manage their illness (Holt *et al*, 1998). Although there seems to be a fear of discrimination, the data from the current study suggests that this fear is based on perception as none of the participants have experienced traumatic events as a result of being identified as HIV-positive (Almeleh 2004). Disclosure during the symptomatic phase resulted in positive responses from significant others which led to assistance in accessing appropriate health-related support, while disclosure during asymptomatic periods led to expected emotional support.

In six of the eleven cases in this study, disclosure occurred during stage 3 or stage 4 of HIV disease, that is, when the person's immune system was severely compromised and were experiencing serious opportunistic infections. This does not necessarily indicate that the participants waited lengthy periods of time to disclose, but rather they were at these late stages when they were diagnosed and hence needed immediate support. Alonzo and Reynolds (1995) attribute this to the fact that the person is no longer able to hide his or her status as the disease becomes clearly visible, and treatment, care and support become necessary for survival. The biophysical effect on disclosure is evident in other studies where disclosure patterns varied according to psychological conditions, fear of stigma and stage of the disease (Holt *et al*, 1998).

The specific form of support required plays an important role in the disclosure process. Participants chose to disclose so that their significant others would know the appropriate treatment for diseases and symptoms caused by HIV and a compromised immune system. This included a desire not to be taken to traditional healers because they thought that traditional medicines would do more harm than good. As noted earlier, anecdotal evidence from PLWHA suggests that health-professionals in clinical settings discourage the use of traditional medicine (Wreford 2005; Mall 2005). This is mainly due to the

purgative nature of traditional medicines and hence a negative pharmacological interactions with HIV medications (Mall 2005). It is possible that PLWHA use traditional medicine more often than they admit, but deny using them because they have been told not to (Mall 2005).⁹ However, the positive experiences of biomedicine possibly also encourages using a healing system with ‘proven’ results. This clearly plays out in the reasons for disclosure described in the current study.

In five cases, the participants were healthy at the time of disclosure. Health status is again an important factor, although in a different context. In these five cases, diagnosis occurred during pregnancy, so they needed to undergo MTCTP to prevent transmitting HIV to their unborn children. In four of these five cases, the primary motivation for disclosure was based on educating others about HIV from both social and biological perspectives. This is consistent with a study of 322 HIV-positive African-American women, where content analysis highlighted motivations that included a desire to increase awareness around HIV/AIDS and to overcome AIDS-related stigma through disclosure of their HIV-status to significant others (Sowell *et al*, 2003). Similarly, in a qualitative study in two South African communities, Norman *et al* (2005) found that disclosure was used as an opportunity to educate significant others and challenge HIV/AIDS stigma.

When the participants’ health was not compromised, they had no need for health-related social support. The stories of Buyiswa and Ncumisa give weight to this suggestion as both were diagnosed while pregnant but had never experienced serious opportunistic infections. Although the timings of their disclosures were substantially different, both disclosed to their families, at carefully selected times, as a way of nurturing good familial relationships, receiving emotional support, and educating their significant others about HIV/AIDS. Another four participants that were diagnosed while pregnant disclosed some time after their diagnosis (between nine months and two years). Medley *et al* (2004) showed similar findings where rates of disclosure in developing countries were lowest when the person was diagnosed while pregnant.

For those participants that had experienced serious symptomatic phases and had been cared for by significant others, they expressed similar feelings about wanting to disclose in order to nurture these important relationships. There seemed to be a number of reasons for this kind of motivation. Firstly, they felt a responsibility to disclose to their significant others and maintain relational ties

⁹ See http://www.irinnews.org/S_report.asp?ReportID=53090&SelectRegion=Southern_Africa accessed 7/05/06

as they had been looked after by them when they were sick and it would be unreasonable to keep this secret from them. From a risk perspective, the risks of negative consequences were low considering that their significant others had already invested substantial time and resources in giving support to one of their sick loved ones (Greene *et al* 2003). Secondly, they did not want their significant others to hear of their HIV-positive status from a third party and cause 'boundary turbulence', that is, where privacy boundaries are breached without the consent of the person whose secret is being betrayed (Greene *et al* 2003; Petronio 2002). This might aggravate an already sensitive situation where some of the women had been keeping their diagnosis secret for some time (*Ibid.*). From the perspective of the significant other, it seems rational to expect honesty considering the time and effort they put in to giving their loved ones support.

From both relational and educational perspectives, many participants felt a need to counter perceptions of morbidity and mortality when disclosing to significant others. They wanted to challenge existing false popular perceptions that you had to be sick to have HIV and to educate others that HIV is a chronic *manageable* illness and not a death sentence. American studies suggest that PLWHA worry that those they disclose to will think they are dying and that this will be a very painful experience for everybody involved (Greene *et al* 2003; Petronio 2002). In fact, the current study respondents' suspicions were confirmed by the reactions of their significant others when they disclosed their HIV status as in the cases of Ncumisa, Nokwanda and Nonceba. Ncumisa spoke about how those she disclosed to reacted as if her death was imminent although she was not yet on ARV treatment due to her excellent health. She wanted to be treated as normal when she disclosed, because she was healthy, and therefore aimed to educate others regarding her situation and the biophysical realities of HIV/AIDS. These findings are consistent with other international studies where PLWHA do not want to be a burden on others (Holt *et al* 1998). They want to remain contributing members to their respective households and society.

At certain times and under certain circumstances, it is necessary to engage with significant others or friends for support, but at other times, it is also necessary not to burden others and hence risk beneficial relationships (Greene *et al* 2003). In a study of disclosure in South India, Chandra *et al* (2003) attributed the higher rates of disclosure to family members as opposed to non-family members to the notion that the family is the primary support system in India. Similarly, O'Brien *et al* (2003) found in a diverse sample of 269 HIV-positive people in New Orleans, USA, that people in advanced stages of HIV preferred to draw upon the support of close family members as opposed to outsiders (69.8% of respondents disclosed to immediate family members as opposed to 27% to other relatives and 26.4% to friends). In the current study, participants generally

balanced the potential negative consequences and risks of disclosing with the potential support given particular relational histories and qualities. They then disclosed to the people they trusted most and could foresee minimal negative consequences in these valuable relationships. This may suggest that HIV-positive people may feel distanced from general society and more dependant on significant others as their illness progresses and they experience more severe opportunistic infections.

Conclusion

The impact of disease progression on HIV status disclosure has been recognised in numerous studies in the industrialised world (Petronio 2002; Greene *et al* 2003; Holt *et al* 1998; Alonzo and Reynolds 1995; Serovich 2001). Yet there has been a notable lack of research into this particular aspect of HIV/AIDS in the South African context. This is even more so in the context of disclosure to significant others, as the majority of studies in both the industrialised and developing world have focussed exclusively on disclosure to sexual partners.

Previous theoretical models of disclosure have not placed much emphasis on the social and biophysical context in which individual decisions regarding disclosure are made. Rather, these models have focussed on the reasons for disclosure, the choices of disclosure recipients and the resulting consequences. The individual's health situation at the times of diagnosis and disclosure, in addition to the impact of this changing health status on the social context in which PLWHA live, have been underreported and understudied.

The changing effects of the disease have a significant impact on the changing life experience of living with HIV. Alonzo and Reynolds (1995) define the experience of living with HIV/AIDS as a dynamic bio-psychosocial experience over time. This is a useful conceptual basis from which we can begin to understand the complexities of living with HIV/AIDS. People can and are diagnosed with HIV during different stages of HIV infection, symptomatic and asymptomatic, and are therefore confronted by different social and individual circumstances as the disease progresses.

The narratives of the research participants illustrated the situation where their individual and social experience of living with HIV/AIDS was significantly influenced by false perceptions of HIV/AIDS in their communities. For some participants, even before they were diagnosed HIV-positive, they experienced AIDS-related stigmatising attitudes and behaviour as a result of visible signs of illness. Additionally, later on in the disease trajectory (especially those on HAART or those who have never experienced symptoms), the participants had

experienced challenges to their HIV-positive status due to their excellent physical health and lack of visible symptoms. This range of experience is clearly a result of the changing biophysical effects of HIV disease on the individual, and the resulting confusion due to the fact that no other disease works in a similar way. Importantly, by not disclosing during times of good health due to fear of stigmatisation, and disclosing more frequently during periods of ill-health, HIV/AIDS is popularly viewed as a debilitating and fatal disease and not one in which the person may live in good health.

For the majority of the study participants, the decision to disclose was significantly influenced by the different stages of HIV disease and the visibility of opportunistic illnesses. Participants were either diagnosed when they were in stage 3 or stage 4, or when they were pregnant. Due to fears of AIDS stigma many attempted to keep their diagnosis a secret. This changed when they reached a stage of HIV where opportunistic infections such as TB, pneumonia or weight loss resulted in a need to access treatment, care and support. In some cases, the time between diagnosis and disclosure was a result of coming to terms with their diagnosis, and overcoming the potential risk of disclosure that was, to a large extent, determined by perceptions and fears of AIDS stigma and discrimination.

Once they had dealt with the potential risk, they could then decide who to disclose to and when to disclose. This process was mediated by the onset of visible and severe opportunistic infections, and genuine need for support. The specific form of support required also played a significant role in the disclosure process. Participants wanted to disclose in order that their significant others knew the appropriate treatment for HIV-specific illnesses, and/or in order to be taken to traditional healers where they thought the medicines would do more harm than good.

When the participants had not experienced severe opportunistic infections, different motivations for disclosure were evident. Women are in most cases tested and diagnosed when they are pregnant as is shown by numerous studies (5 out of 11 of the participants in this study). They are not yet experiencing opportunistic infections as they are not in the advanced stages of HIV disease. The data from the current study showed that when the individual had not experienced opportunistic infections, disclosure occurred due to symbolic concerns such as challenging stigma and educating others. Importantly, 100% of these individuals (who were diagnosed while pregnant, and not sick) initially disclosed for these reasons.

In all cases, participants carefully selected disclosure recipients according to their needs at the specific times. Because they recognised the significance of

important relationships in their lives, the relational context is an important site of experience. Participants chose to disclose to those individuals that were already providing support or had the potential to provide the support they required. Disclosure was also a chosen route in order to nurture these important relationships where bonds of caring, reciprocity, continuous support and trust already existed. Two of the participants disclosed purely for reasons based on relational quality, as they had never experienced HIV related illnesses and therefore never needed health related support from their significant others.

The results from the current study suggest that the unique and changing biophysical nature of HIV/AIDS has a significant effect on the timing and motivation concerning people's decision to disclose their HIV-status. HIV-positive individuals have to negotiate through the disclosure process in a socio-cultural context characterised by misguided and stigmatising perceptions of HIV/AIDS. Consequently, the motivations for disclosure and the choice of recipients are based on a complex and subjective combination of countering false popular perceptions of HIV/AIDS, and accessing appropriate treatment, care and support. Further research on HIV-status disclosure in Africa needs to be conducted and theoretical models developed, where HIV/AIDS is viewed as a dynamic and changing bio-psychosocial experience in which disclosure is both a response to, and in turn shapes, the social world of people living with HIV/AIDS.

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