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**‘Let Me Be Quiet’:
The Dilemma of HIV Disclosure**

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Abstract

This paper argues for a differentiated approach to understanding disclosure of HIV status in a South African township. It suggests that there are two models of disclosure: partial and full. There are benefits for PLHA in both forms of disclosure resulting in improved health and well-being. Disclosure can also play a role in prevention as it can facilitate initiation of safe sex practices. However, the benefits are limited in the partial disclosure as there are challenges related to health-seeking behaviour, stress release and initiation of safe-sex practices. The paper describes partial disclosure as a dilemma between, on one hand, feeling free from secrecy, improved health and well-being and being able to solicit support, and on the other, fear of stigma and discrimination. It argues that a crucial aspect in the choice between partial and full disclosure is how PLHA deal with stigma and self-stigmatisation, related to a conceptualisation of HIV as a disease the bearers bring unto themselves through ‘immoral’ behaviour. It suggests that those who chose partial disclosure dealt with stigma through managing their disclosure by seeking out people who were unlikely to stigmatise and likely to be supportive. They dealt with self-stigma through ‘insisting on innocence’, repositioning themselves within the ‘guilty’/‘innocent’ binary as ‘innocent’ without challenging the discourse of illness as personal responsibility. For the majority of those who disclosed fully, disclosure was experienced as a dilemma in the same way as for those who disclosed partially. In these cases, the dilemma was resolved by confronting stigma and refuting the stigmatising discourses that link HIV with personal responsibility and morality. Some informants who disclosed fully shortly after the diagnosis did not experience self-stigma and did not fear external stigma because they did not associate HIV with personal responsibility. Finally, this paper concludes that improved disclosure rates as well as a change from partial to a more inclusive or full disclosure is essential to realise the full benefits of disclosure, a change that is linked to challenging the conceptualisation of HIV as a condition linked to personal responsibility and ‘immorality’.

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Antiretrovirals
HIV	Human Immunodeficiency Virus
NGOs	Non-governmental organisations
PLHA	People living with HIV/AIDS
SANCO	South African National Civic Organisation
STD	Sexually transmitted disease
TAC	Treatment Action Campaign

Introduction

It is a cloudy afternoon in a township near Cape Town. Gladys, a 42-year-old woman, is on her way to a support group meeting for HIV-positive in the local community centre. No one is aware of Gladys's destination on Wednesday afternoons, though today is different - Gladys is wearing the group's T-shirt. A big red AIDS ribbon and the words HIV-positive feature prominently on her T-shirt. While many activists, such as those belonging to the Treatment Action Campaign (TAC), use T-shirts to show solidarity and challenge stigma without indicating their status, this T-shirt is only for members of the support group. In this particular context, wearing the T-shirt is an indication that the bearer is HIV-positive. The T-shirt is not the only item that makes Gladys appear different today. Despite it being a cloudy day, Gladys has hidden her eyes behind a pair of big sunglasses and covered her hair with a scarf. Yet it seems as if she is protecting herself, not so much from the sun's glare, but rather from glaring eyes. Later, she explains that she did not want people to recognise her. This was the first time she wore the T-shirt, and she later explains that she does not have the courage to do it again.

In contrast to Gladys, 32-year-old Phelo arrives to the support group meeting wearing his HIV-T-shirt with a smile. Phelo, who is one of the leaders of the support group, is one of the few people living with HIV (PLHA) in this township who has fully disclosed his status, symbolically showing this by wearing T-shirts that clearly identify him as HIV-positive. It is on his insistence that the support group members wear the T-shirts for meetings - hence Gladys's decision to wear the T-shirt - despite her fear of being recognized. Except for Gladys, only a few others heeded his call, and, at subsequent meetings, only Phelo continued to display his HIV-positive identity.

This paper explores how disclosure is experienced and managed by a group of HIV-positive people in a South African township with high HIV prevalence. It explores why women like Gladys experience disclosure as a dilemma, looking at both the risks and the benefits involved in disclosing. After a short literature review and description of the research methodology, this paper identifies two models for disclosure: partial disclosure and full disclosure. Partial disclosure is characterised by PLHA seeking out specific people whom they choose to disclose to. Partial disclosure is a process spanning years with the first disclosure delayed by several years following diagnosis. Full disclosure is a public form of disclosure where PLHA do not hide their status, and do not selectively disclose to particular people. Some PLHA, that disclose fully or publicly, demonstrate their HIV-status by wearing 'HIV T-shirts'.

This paper suggests that the majority of PLHA experienced disclosure as a dilemma. On the one hand, disclosure was perceived to improve health and well-being, facilitate support, and provide cathartic relief from secrecy. On the other hand, the respondents feared stigma, rejection and exclusion following disclosure. The majority of PLHA solved this dilemma through disclosing partially and managing their disclosure carefully. Partial and delayed disclosure enabled PLHA to minimise the risk of enacted stigma, discrimination and exclusion, while at the same time achieving some of the rewards in disclosure, namely feeling free, improved health and well-being and being able to solicit support. The fear of stigma, discrimination and exclusion was minimised through seeking out confidantes who were unlikely to stigmatise and likely to be supportive. Disclosure occurred after a period of monitoring and testing people's stigmatising attitudes and behaviour. In addition, disclosure was preceded by a period where PLHA dealt with self-stigma by positioning themselves in relation to a guilty/innocent dichotomy, based on a conceptualisation of HIV as a condition associated with 'immorality' and personal responsibility. They 'insisted on innocence' either through insisting on lack of knowledge about HIV prior to diagnosis or through emphasising contracting HIV through a monogamous relationship.

Full disclosure amongst informants in this study was rarer than partial disclosure. One group of people who disclosed fully did so after first disclosing partially. They experienced the same dilemma as those disclosing partially, but chose to resist stigma, and especially the discourse that associates an HIV diagnosis with personal responsibility and 'immorality'. They were motivated by a wish to raise awareness and involved in activism, which helped them resist or risk stigma. For others, the fear of stigma was absent, enabling them to disclose fully shortly after diagnosis.

The paper argues that disclosure had a positive impact on the health and well-being of PLHA irrespective of whether disclosure was full or partial, but the benefits were limited in the partial disclosure as was the impact on prevention. Firstly, disclosure frequently excluded sexual partners or disclosure to partners was delayed. Because of this, safe sex practices were not necessarily instigated. Furthermore, partial disclosure meant that PLHA continued to spend considerable energy on managing the disclosure. This reduced the effect of being unburdened and free of stress. In addition, health-promoting behaviour was compromised by the selective nature of partial disclosure. When PLHA did not disclose to live-in-partners or people in the same household, there were serious challenges to ARV adherence and other forms of health seeking behaviour. Finally, the delay in disclosure, both in the partial and full model, also meant that the benefits were delayed.

The paper goes on to suggest that the full potential positive impact of disclosure can only be realised by a shift from partial disclosure to a full or more inclusive form of disclosure that includes sexual partners and people living in the same household. Having identified stigma as a key factor in choosing partial disclosure, the paper considers how partial disclosure is managed by managing the risk of external stigma as well as self-stigmatisation. It compares this to those who disclose publicly, suggesting that the fear of stigma was either absent or resisted. For many, this was facilitated by activism or by taking on a role as advocates in the community.

This paper concludes that stigma needs to be addressed in order to encourage a shift from a partial disclosure to a more inclusive disclosure. It suggests that the belief that HIV is an 'immoral' condition associated with personal responsibility needs to be changed, and explores how this notion was resisted and challenged by those who found support in an activist/advocate identity. However, full disclosure remained rare in this township because there were limited opportunities for HIV activism and because support groups, like the one Gladys was a member of, did not challenge stigma or the belief that HIV is a condition that the bearers bring unto themselves through 'immoral' actions.

Literature Review and Study Rationale

For few conditions is disclosure as important yet as problematic as it is for HIV. Disclosure has become a requirement for accessing treatment in public health care facilities in South Africa (Deacon 2005:77). Clinics require that people who start on antiretroviral (ARV) treatment disclose their status to at least one person and solicit the support of a 'treatment buddy' to assist the patient in adhering to the ARV treatment. Non-disclosure, on the other hand, poses challenges to ARV-adherence. Norman, Chopra and Kadiyala (2007), refer to literature suggesting that PLHA skipped ARV dosages because they could not take their medication without being observed. Mills, de Paoli and Grønningsæter (2009) argue that non-disclosure is a barrier both to starting ARV treatment, and to adherence.

Research by Paxton (2002) suggests that disclosure has a positive impact on the health and well-being of PLHA. Paxton notes that by 'speaking out' and facing HIV-stigma, PLHA experience a sense of psychological release or 'liberation' from the burden of secrecy and shame, leading to alleviation of stress and improved health. It is, however, important to note that her study involved activists from a number of countries who had disclosed publicly; the research findings may not reflect experiences of those who have only disclosed partially and who have not found support in an activist community/organisation.

Conversely, stigma may undermine the positive impact of disclosure on mental health. One study concludes that disclosure does not necessarily lead to better mental health because of stigma (Comer, Henker, Kemeny and Wyatt, 2000). Simoni, Mason, Marks, Ruiz, Reed, and Richardson (1995) also suggest that benefits of disclosure vary amongst different (social) groups. These studies point to the importance of contextualising disclosure.

Disclosure may also play a role in HIV-prevention. Initiating safe sex practices is easier when partners disclose to each other. Norman et al. (2007) suggest that reduced incidence of HIV infection cannot be realised without disclosure by HIV-positive individuals (Norman et al., 2007:1775). A survey conducted in Cape Town found that 42 percent of HIV-positive respondents did not disclose their status to their recent sexual partners, and non-disclosure was linked to unprotected sex (Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo, 2007).

Thus, the literature is inconclusive in terms of the benefits of disclosure on the health and well-being of PLHA; while one study suggests that non-disclosure to sexual partners is common and associated with unprotected sex. This study seeks

to understand the impact of disclosure on both the health and well-being of PLHA and on prevention amongst people in a South African township by proposing that disclosure should be view in terms of two different models: partial disclosure and full disclosure. In contrast with the above-mentioned literature on disclosure (Comer et al. 2000 and Simoni et al. 1995), it argues that this distinction is crucial to understand the benefits of disclosure as well as how risks are managed. It examines the challenges and limitations in the partial model as well as the reasons why full disclosure is rare and why partial disclosure is preferred in this township.

Methodology and Research Objectives

This paper is based on ethnographic research carried out in 2007 in a South African township situated in the outskirts of the Cape Town Metropole and home to about 10,000 South Africans, the majority of whom speak Xhosa as a first language. Poor living conditions contribute to a number of social and health problems. 32 percent of pregnant women tested positive at the local clinic in 2006, a figure slightly higher than the national prevalence rate of 29.1 percent (South African HIV and AIDS Statistics 2006¹) for women attending antenatal clinics.

There are a range of health and social services available to people living in the township. The township is serviced by two public health clinics: one that treats young children, and people with STDs, HIV and TB. This clinic is known in the community as the 'AIDS clinic'. The second clinic treats all other diseases. There are between 30-40 *sangomas* and *inyangas* (traditional healers) who work in the township. There are two support groups for PLHA, one run by the NGO Nakekela, the other established by two HIV-positive community members and supported by a number of churches.

The research methodology was developed to explore four main objectives: 1) to understand which factors influence the decision to disclose and how to disclose; 2) to understand how PLHA experience and manage the process of disclosure; 3) to understand whether disclosure is beneficial or detrimental to PLHA; and, 4) to understand the role of disclosure in prevention.

¹ This figure is from The South African Department of Health Study 2006, cited in South African HIV and AIDS statistics 2006.

As a qualitative study, this study used participant observations, open-ended and semi-structured interviews, and focus groups as means of data collection. To understand different forms of disclosure, I identified both people who had disclosed to a few people and people who were fully open about their status. As one of the aims of the study was to understand which factors influenced the decision of whether to disclose or not to disclose, I made attempts at identifying people who had not disclosed their status with help from health professionals at the local clinic. Despite repeated promises of ensuring their confidentiality, this proved impossible. This presents a limitation for this study. However, many PLHA only disclosed their status after years of keeping silent. Asking them to reflect on their feelings, reasons and experiences in retrospect is therefore one avenue to understanding both decisions of non-disclosure and disclosure, even though they may have ‘airbrushed’ their self narratives somewhat.

Another challenge was finding male informants. Generally, men in the township were reluctant to disclose. The support group that I attended had 20 members, only one was male. Attempts to find male informants through assistance from the clinic staff and through the support groups were to no avail. Therefore, by default, this study only includes one male PLHA.

Ethical approval for this study was granted by the Department of Social Anthropology at the University of Cape Town. In order to protect their confidentiality, I have given all PLHA pseudonyms and limited identifying information where necessary.

Findings and analysis

This paper suggests that there are two models of disclosure: partial disclosure and full disclosure. It suggests that there are benefits for PLHA in both forms of disclosure in form of improved health and well-being and that disclosure can also play a role in prevention. However, the partial disclosure presents limitations to the benefits, particularly when PLHA do not disclose to sexual partners. The findings describe partial disclosure as a dilemma between, on one hand, feeling free from secrecy, improved health and well-being and being able to solicit support, and on the other the risk of experiencing stigma and discrimination. It suggests that this dilemma was managed by seeking out people who were unlikely to stigmatise and likely to be supportive as confidantes. It also suggests that self-stigmatisation was dealt with through a process of ‘insisting on innocence’, refuting personal responsibility for being HIV-positive. The paper suggests that for the majority, full disclosure was experienced as a dilemma in the same way as for those who disclosed partially. In these cases, the

dilemma was resolved by confronting stigma and refuting the stigmatising discourses that distinguish innocent and guilty. This was facilitated by becoming an activist/advocate, something that enabled PLHA to resist self-stigmatisation and confront stigma. For some, notably the only male informant, disclosure was not experienced as a dilemma. In his case, the fear of stigma was absent, enabling full disclosure. The conceptualisation of HIV as a condition associated with ‘immorality’ and personal responsibility was replaced by a focus on structural issues - like poverty – which were labelled as the main driver behind the epidemic.

The most prevalent form of disclosure was a partial disclosure, where PLHA selectively disclosed their HIV status to a few people. In some instances, disclosure was limited to a support group, thus disclosing only to people who were also HIV-positive. It was preceded by seeking out confidantes that were unlikely to stigmatise and likely to be supportive and by a repositioning of themselves as ‘innocent victims’. This form of disclosure often excluded sexual partners. The selective form of disclosure was for the majority of informants a process that spanned several years with the first disclosure occurring several years following initial HIV-positive diagnosis. The sentence ‘I was not ready’ was used repeatedly, indicating the processual nature of disclosure. For example, Andile, 36, had kept her diagnosis a secret for six years. She first disclosed to her boyfriend. Three years after her first disclosure, she confided in her mother, and subsequently she disclosed to her siblings. Gladys, mentioned in the introduction, is another example. She disclosed to her partner four years after her diagnosis, then to her children and to a friend. Aside from the support group members, Gladys had only disclosed to these four people. She did not disclose to the friend she lived with.

For PLHA who disclosed partially, disclosure was experienced as a dilemma. There were strong motivators for wanting to disclose, but equally strong fears preventing disclosure. On the one side there was a need to free oneself from the burden of secrecy, a need to solicit support, a sense that disclosure was the right thing to do, and a belief that disclosure has a positive impact on health and well-being. Then there were factors that discouraged people from disclosing, such as the fear of stigma, rejection, social exclusion and loss of support.

Andile’s story illustrates this dilemma. The fear of stigma and discrimination loomed large and influenced her decision not to disclose. She feared stigma in the form of people talking negatively about her, labelling her, making jokes about her, and calling her names. She feared being discriminated against and was convinced that her safety may be jeopardized if people came to know her status. The following quote demonstrates this:

‘When people know that you are HIV-positive, they get scared; they don’t want to share their food and other things. When I got sick, I did not know how the illness was transmitted. I just thought that I was going to die. The diagnosis was like a death sentence.’ (Interview with Andile, 2007)

Her fears were partially based on her knowledge of what had happened to other PLHA whose status had become known. Because of these sentiments, Andile did not consider disclosure as a viable option when she was first diagnosed with HIV. Instead of telling her boyfriend, she packed her bags and ‘fled’ Johannesburg to Cape Town where she had family. Andile also grappled with self-stigma. Her HIV-positive diagnosis made her feel ‘like she was not a person’. Prior to her own diagnosis, Andile had been convinced that only ‘prostitutes and ‘loose women’ contracted HIV. These beliefs made her experience self-stigmatisation when she was diagnosed.

While disclosure seemed impossible, Andile also felt that keeping her diagnosis a secret was a burden that was ‘eating her up’. Andile longed for support during this period. She felt lonely and lost and resorted to drinking alcohol to cope with the stress. The desire to disclose and the fear of doing so presented a cruel dilemma. Yet, in the end there was no choice, ‘I kept telling myself that if I talk, people will run away and they will not drink from the same cup or they will hurt me. So I said to myself, ‘Let me be quiet.’” (Interview with Andile, 2007)

When she met her new boyfriend, she did not disclose her status because of these fears. She was convinced that if he knew about her status, he would end their relationship. Andile did not initiate safe sex practices and became pregnant. At an antenatal check-up, the clinic sister suggested an HIV-test and Andile decided to test even though she knew her status. Contrary to her first test, this test was accompanied by a counselling session; in these counselling sessions the counsellors strongly advised women to tell their partners about their status in order to make it easier for them to take Nevirapine and reduce the risk of transmitting the virus to their babies. Consideration for the health of her unborn baby made Andile decide to tell her boyfriend, and her fears turned out to be unfounded. Instead of chasing her away, he replied that he loved her and that nobody knew where the disease came from. Her boyfriend refused to get tested, citing that he believed in God and would just pray. Andile took Nevirapine and her daughter Siyanda was born HIV-negative.

However, Andile still felt that disclosing to her family was too risky. Only after she started training to become a counsellor for the NGO Nakekela, did she decide to disclose to her mother, almost nine years after her diagnosis. Her

mother was supportive. A few months later, Andile told her sister, and her fear of rejection was justified:

‘Since I told her, she has not been the same. Before, she would come to my house. She would ask me if I had cooked *papa* (maize meal porridge) and say that she would like some. Since I told her I am HIV-positive, she does not come to my house anymore. She used to visit, to phone, and we used to go for walks together. Now...I don’t know what happened, whether she is scared or what, but it is not the same. My sister, she used to love me...’ (Interview with Andile, 2007)

Despite her elder sister’s rejection, Andile decided to tell her two other siblings - they were supportive. Aside from her elder sister’s reaction, Andile’s overall experience of disclosure was positive. She felt free and unburdened of the stress of keeping her diagnosis a secret: ‘I am not the same anymore – because before I was not free – after (disclosing) you feel much better. There is nothing eating your heart up. You just feel okay’. (Interview with Andile, 2007)

Phumlani’s story also exemplifies the dilemma of disclosure and the role of HIV-stigma. Phumlani, 26, tested positive in 2004. She limited her disclosure to the support group she attends. Phumlani’s fear of disclosure was partly fuelled by her experience with disclosing to her previous boyfriend, who responded by blaming her for ‘bringing HIV into their relationship’. Phumlani felt a strong need to confide in her mother to solicit support, but feared her mother’s reaction. She had also not disclosed to her boyfriend, whom she was to marry in six months, because she feared he would leave her because he openly criticized and spoke ill about people with HIV. Phumlani felt she had no choice but to keep her status a secret. Consequently, she had to hide anything that might indicate her status, such as attending a support group, keeping clinic appointments and taking immune boosters. The couple did practice safe sex for birth control. Yet, Phumlani explained that it might become increasingly difficult to practice safe sex once her marital status changed as her husband might not want to practice birth control after being married because he expected her to bear children.

Andile and Phumlani’s dilemma resonated with many of the other informants’ narratives. PLHA described disclosure as the ‘right thing to do’. Hiding their condition felt like a burden, and there was a strong urge ‘to let it out’. Informants described feeling ‘free’ after disclosure. One woman, Daniswa, explained that telling someone was like ‘coughing it up’. Others mentioned that, once you disclose, you feel free and can start dealing with your status. Even when informants did experience rejection there was a sense of being ‘freed’ from a burden.

Disclosure was perceived to have a positive impact on their health and well-being. Many informants, like Andile, were convinced that hiding their HIV status was detrimental to their health and increased their stress level. On the contrary, disclosure made them feel 'healthy'. 'You are less stressed and feel better afterwards,' explained one informant. Another argued that 'all her sickness was healed'.

Disclosure also enabled several women to ensure the health of their babies. Andile is one example of this, Daniswa another. Daniswa, a 27-year-old mother with a 4-year-old daughter, was faced with a dilemma between risking having her HIV-positive status exposed and jeopardizing her child's health. She was given Nevirapine, an ARV, to take during labour to reduce the risk of passing the virus to her baby. Daniswa had chosen not to disclose to her family for fear that they would stigmatise her if they knew her status. When in labour, surrounded by her relatives, she was in a quandary as she had to take her medication - should she risk exposing her status or risk her baby's health? After much vexing, she took the medicine under the pretence that they were painkillers.

Partial disclosure also enabled other forms of health-seeking behaviour. The respondents noted that it became easier to get support to take ARVs, keep clinic appointments, use condoms, and otherwise lead 'healthy' lives. This was especially important when HIV-positive women lived with their partners. In these cases non-disclosure posed challenges to the health seeking behaviour such as seeking treatment and adhering to ARVs, as already illustrated in Phumlani's narrative.

In contrast, Joyce, 36, found that her partner was very supportive after she disclosed to him. For example, he encouraged her to take her ARVs correctly and to keep her clinic appointments. Another woman noted that after telling her partner about her status, she did not have to hide her ARVs and found it easier to take them on time. The patients' advocate at the local clinic also noted that patients who had a 'treatment buddy' had higher adherence. Other women explained that they started using condoms after disclosing to their sexual partners, something that they were not able to do before disclosure. Gladys's experience illustrates this. Prior to her disclosure to her boyfriend, she did not even attempt to start using condoms. After her disclosure to her partner, they started using condoms. While her partner was not willing to test, he agreed to practice safe sex. Thandeka, 34, who chose to disclose to her current partner immediately after their relationship started, said that this enabled them to practise safe sex.

However, disclosure to partners was rare, and non-disclosure to partners was associated with not practicing safe sex. Thumeka, 26, is an example of this. She had recently met her boyfriend and chose not to use condoms or disclose her status to her new boyfriend because she feared she would lose him if she did. In some cases, such as Phumlani's, women attempted to practise safe sex without disclosing, but – as shown – this was problematic.

The need for support was another significant motivator for partial disclosure. For all PLHA who were members of the support group, disclosure within the support group enabled them to receive both emotional and material support (in the form of food parcels, vitamins and immune boosters). Disclosure to family members, neighbours and partners also enabled them to receive both material and emotional support. One woman explained the importance of disclosing to family members or neighbours because she argued that they could provide support during periods of illness. Another woman argued that disclosure enabled her to get support from her family to come to terms with her condition.

Despite the many rewards of disclosure, there were also risks. Stigmatisation was the main risk. Consistently, informants feared being spoken ill of, being labelled, being called names, having fingers pointed at them, being gossiped about and sworn at – and this prevented them from disclosing.

Many informants feared stigma in the sense that Goffman described it: as 'an attribute that is deeply discrediting' (Goffman 1963:3) with the stigmatised person viewed as 'not quite human' and 'disqualified from full social acceptance' (ibid: 5). Goffman linked stigma to having a blemished character and to deviant behaviour. This leads to the creation of a spoiled social identity, which is dealt with by concealing features which identify the individual as possessing these undesirable differences.

Andile's comment that people will "talk to you as if you are not a person" resonates in comments from other informants such as the following: "people will look at you as if you are a bad person"; "people look at you if you are not right". Gladys, who had disclosed to four people, reflected on how people claimed superiority by devaluing PLHA because they see themselves as 'immune' to HIV. She referred to people making the following claim, "Me, I am much better than you because I cannot get HIV".

In addition, stigma was linked with discrimination, exclusion, rejection and loss of support. One woman, for instance, explained that people point fingers at HIV-positive people, telling others to avoid them. Many PLHA were concerned that people would not want to share things such as food with them, or would refuse

to use the same utensils. Andile's sister's refusal to eat at her house is indicative of this. Daniswa had a similar experience when her cousins refused to share food with her because they feared that, "maybe one day you [Daniswa] will put HIV in our food or maybe you will sleep with our boyfriends and give them HIV".

Most PLHA responded to the dilemma of disclosure by carefully managing their disclosure in order to minimise stigma and discrimination and ensure support. They sought out people who were less likely to stigmatise and avoided those who were unlikely to be supportive. PLHA disclosed to people they trusted, after testing reactions or monitoring their attitudes. Furthermore, they disclosed to one person first, observed their reaction, and then disclosed to another and so on - such as described in Andile's story. Phumlani's narrative also serves as an example. Realising that her mother was unlikely to be supportive, Phumlani chose not to disclose her HIV-status to her. This followed a period where she had monitored her mother's attitude. This monitoring made Phumlani realise that her mother would not accept that her daughter had HIV because she, according to Phumlani, was convinced that you get HIV either from witchcraft or 'sleeping around'. Daniswa's story illustrates how some people deliberately tested people's attitudes towards PLHA prior to disclosing to them. She explained that she jokingly told her neighbours, who asked her why she was fat, that it was due to the tablets she took for HIV. By joking she was able to protect herself, while at the same time testing their attitudes. When they responded negatively, she decided not to confide in them.

The second part of managing disclosure related to self-stigmatisation - an internal sense of shame. With their HIV-diagnosis, female informants were 'transformed' into deviant and dangerous women and their identity had become 'spoiled' in Goffmann's (1963) conceptualisation of the term spoiled identity. Daniswa narrated it in the following way, 'I had always thought that only 'bad' women could get HIV. All of a sudden I was one of those women' (Interview with Daniswa, 2007). Before disclosure was possible, a reconfiguration of these spoiled identities had to take place. This reconfiguration took place through repositioning themselves in relation to a guilty/innocent dichotomy by 'insisting on innocence'.

The internal stigma related to two factors: that HIV was seen as the bearers' responsibility and that it was associated with 'immorality'. Because HIV is transmitted sexually it is understood, at least for women, as a sign of sexual transgression and deviance. The salience of this discursive construction can be seen in the fact that all informants in this study used exactly the same stigmatizing labels to describe women who they, prior to their own diagnosis, perceived to be likely to contract HIV: 'prostitutes', 'loose women', 'bitches',

‘sluts’, ‘women who like boyfriends too much’, ‘women who sleep around’, and ‘women who sell their bodies’.

The first way of ‘insisting on innocence’ was by professing a lack of knowledge about the disease before diagnosis. In doing so, they refuted responsibility for their condition. Particularly illustrative of this is Gladys’s insistence on ignorance, by claiming that she had never heard of the disease in 2004, when she was diagnosed. She reiterated this on a number of occasions, but later conceded that she ‘chose’ not to hear about HIV/AIDS because she feared it.

Similarly, Nozuko was diagnosed with HIV in 2004, during a pregnancy. Nozuko claimed that she had never heard of HIV. Later it became clear that she *had* heard about HIV, but ‘chose’ to remain ignorant. The following quote illustrates how this was linked to the fact that by acknowledging being at risk she would admit to having a ‘blemished’ character:

‘In the community, if you are HIV-positive people look at you like... (She stops talking as if even speaking about it is impossible, but her body language indicates that she ‘shrinks’ as a person) ... In the community, they look at you as if you sell your body.’ (Interview with Nozuko, 2007)

Even Phelo, the male support group leader, claimed ‘innocence’ by insisting that he did not know enough about HIV when he was diagnosed. Despite the training he received to become an HIV-counsellor prior to his own diagnosis, he insisted that there was a lack of information about HIV in 2002 when he was diagnosed.

The most prevalent way of ‘insisting on innocence’ was linked to refuting a blemished character; by reiterating that they were not responsible for their condition through their ‘deviant’ or ‘immoral’ behaviour. For example, Andile explained her reluctance to disclose with reference to the fact that by admitting she was HIV-positive she also admitted that she was an ‘immoral’ woman. Initially, this led her to deny her own risk, and – once diagnosed - made her refrain from disclosure. Through statements such as “I was not that kind of woman’, Andile refuted a blemished character.

Consistently, women claimed respectability by stating that, ‘I only had one boyfriend.’ This became part of an explanation for why they had not seen themselves at risk of contracting HIV and why they were ‘innocent’. This also took the form of changing the view that only ‘loose’ women could contract HIV to a belief that it can happen to ‘respectable’ women. Gladys explained that she previously believed that ‘HIV was only for loose women’, but now realised that

it can happen to ‘women who only have one boyfriend.’ Again, this change occurred in many women as part of a reconfiguration of their own identity in relation to stigma.²

Many HIV-positive women’s claim to innocence was followed by a shift in blame. They charged that men were to be blamed because of their (sexual) behaviour, which they described as ‘immoral’, because men ‘slept around’ and refused to use condoms. This blaming of men was also reflected in explanatory models of transmission mode. Some women explained how the HI virus is transmitted from men to women because women are ‘on their back’ (in a passive, vulnerable position) while men are ‘on top’ during sexual intercourse and the ones ‘giving something’ (i.e. semen) to women. This biological explanation was used to explain how men pass ‘their dirt’ to women, and that women are therefore innocent, while men are responsible for passing on HIV.

The other form of disclosure was a full disclosure, characterised by the HIV-positive respondents who chose not to hide their status and, in some cases, actively ‘displayed’ their status visibly through wearing HIV T-shirts, such as in the case of Phelo. Full disclosure was limited to few people in the township. The informants pointed to five people being fully open about their status in the township, which according to the local clinic had about 800 HIV-positive residents. Sometimes the line between partial and full disclosure was blurred. Nosiphomesu, 33, for instance, had not disclosed fully. Yet, she did not attempt to hide the formula feed that the clinic provides to HIV-positive mothers; notwithstanding that formula feeding your baby according to many informants was perceived as an indication that one is HIV-positive.

Some informants disclosed partially at first and later disclosed fully. In these cases, PLHA experienced the same dilemma as those who disclosed partially.

² It is important to stress that I am not claiming that insufficient knowledge is not an obstacle. Accessibility of HIV-information, especially in the rural Eastern Cape where most of the informants grew up, may be limited. Nevertheless, the inconsistency, in both Gladys’s and Nozuko’s explanations, indicate that this ‘insistence on ignorance’ was part of the defensive denial to being at risk of a stigmatised condition. I am also not suggesting that these women’s stories of HIV exposure through a single relationship are untrue. It is unquestionable that many women contract HIV through what they consider a monogamous relationship, and that their ability to negotiate safe sex is often limited (see Jewkes et al. 2003). Almost all the women who participated in this study were unemployed, and the few that were employed worked as low paid domestic workers. Many relied on their boyfriends for help. Many women claimed that, often, they could not insist on safe sex through condom use, something Andile’s narrative illustrates. Rather, I am suggesting that their strong emphasis on a sexual history with one or few partners, whether true or not, is a reflection of societal norms around female sexuality and individualisation of risk.

Andile's narrative illustrates this. I have previously described how she kept her diagnosis a secret for six years but then first disclosed to her partner and then to her mother and siblings. Yet, becoming fully open about her status only happened 12 years after her diagnosis. After her full disclosure, Andile – like Phelo - visibly displayed her status through wearing a HIV-positive T- shirt.

Andile's decision to disclose fully was facilitated by her encounter with a volunteer from the Treatment Action Campaign (TAC) at her work as a security guard. He encouraged her to join the TAC. Reluctantly, Andile went to a TAC meeting. This changed her view of HIV/AIDS:

‘When I went there I saw these fat ladies and they were healthy and they told me that they were HIV-positive and I felt for the first time that I am not the only one. And I thought: “They are fat and they *live with HIV*” (my italics).³ (Interview with Andile, 2007)

Andile decided to join the TAC and become a community activist. Her story illustrates how activism, along with a changed outlook on HIV and AIDS, enabled her to disclose fully, resist stigma and regain her pride. Andile explained her decision in the following way:

‘Now I am not scared anymore, I am not even shy. I talk to everybody about it. There are people who talk bad about you, but I don't care. Because the TAC has taught me that there is a difference between HIV and AIDS. And there are ARVs. There is hope. It is not just that you must die. Now, I feel much better about myself. I feel proud of my status.’ (Interview with Andile, 2007)

Andile's new found pride and rejection of stigma made her decide that she wanted to raise awareness about the disease to help others. Nozuko, 25, also stated that a wish to raise awareness influenced her decision to be fully open about her status: ‘Nobody talks about HIV. If you talk about it in the community, they do not want to hear about it. But you must talk, because it kills people. You must stand up.’ (Interview with Nozuko, 2007)

For others, the decision to disclose was taken shortly after their diagnosis. Thandeka was one of those. She explained her decision to disclose fully with reference to wanting to raise awareness about HIV and subsequently channelled her activism into starting the support group with Phelo. While Thandeka was not a member of TAC or other civil society organisations she did take on a role as

³ Being fat is seen as a sign of being healthy, in contrast to being thin, which is seen as a sign of having HIV.

‘advocate’ in the community, raising awareness about HIV. She explained that her full disclosure was possible because she had a supportive partner and family. Thandeka also differed from the other women in that she was able to refute stigma and self-stigmatisation from the very beginning, arguing that her HIV-status was not her fault.

Like Thandeka, Phelo disclosed fully shortly after his diagnosis. He was also motivated primarily by a strong wish to raise awareness. In addition, Phelo’s disclosure was facilitated by a lack of fear of being stigmatised or excluded. Hence, he did not experience the dilemma of disclosure like most other informants. Explaining his decision to disclose, Phelo stated that he did not fear stigma, rejection or exclusion because of his gender. He argued that the discourse that associates HIV with ‘immorality’ did not pertain to men. On the contrary, he argued that, for men, multiple partners were part of the ‘natural order of things’. Where most women argued that ‘they only had one boyfriend’, Phelo did the opposite, boasting of being ‘a king’ that had had many women. Phelo’s views on HIV were also different from those of other informants. Where most female informants saw HIV as an issue of personal responsibility and ‘immorality’, Phelo pointed to structural issues such as poverty and high unemployment rates as the root cause of the epidemic.

There were indications that some women began to challenge the conceptualisation of HIV as a condition the bearers bring unto themselves. For example, Joyce initially refuted that she could have HIV because ‘she was not a bad woman’. Later, Joyce began challenging this understanding saying that she was not responsible for her HIV-positive status ‘because I did not buy it in a shop.’ In Joyce’s case this challenge did not facilitate a public challenge to stigma or a full disclosure.

Thus, there were significant differences in how informants who disclosed partially and fully dealt with stigma. Most women, who chose partial disclosure, dealt with stigma by insisting on innocence, while those who disclosed fully either did not experience stigma or were able to resist and reject stigma by challenging and rejecting the ‘innocent’/’guilty’ dichotomy and the discourse of passing blame on the ill. Motivated by a wish to raise awareness, they dealt with the risk of stigma by confronting stigma and taking on a role as ‘advocates’ that aimed to ‘speak up’. The ability to resist stigma was linked to formal activism or channelled into support groups.

Discussion

This paper has presented two forms of disclosure – partial and full – and suggested that the benefits of disclosure should be viewed not only as a question between disclosure and non-disclosure, but between different forms of disclosure. It argues that the benefits associated with disclosure can be realised through improving disclosure rates, and from changing the preferred form of disclosure from delayed and partial to full disclosure or at least a more inclusive disclosure that entails disclosure to partners and people in the same households. Having identified stigma and exclusion as the main factors influencing the decision to disclose partially, the paper argues that the change from partial to a more inclusive form of disclosure must be facilitated by a change in the way stigma is dealt with, and in particular the conceptualisation of HIV as a condition associated with ‘immorality’ and personal responsibility. It suggests that limited opportunity for activism as well as support groups that do not challenge stigma were barriers in this particular community. It also suggests that prior to being able to resist or risk stigma, PLHA in this study had to deal with self-stigmatisation and reconfigure their identity in relation to a ‘guilty’/‘innocent’ dichotomy. How this reconfiguration took place was crucial to the type of disclosure that was chosen.

This study suggests that disclosure has benefits for the health and well-being of PLHA as suggested by Paxton (2002) (cf. Norman et al., 2007). Both these authors relate the benefit of disclosure to the fact that by unburdening themselves from keeping their status a secret, PLHA experience psychological release and less stress. This, they argue, in return has a positive impact on their health. In a similar way, Derlega, Winstead, Greene, Serovich and Elwood (2004) argue that one of the main benefits of disclosure is a cathartic relief of letting go of a secret. This study also found that letting go of a secret made PLHA feel ‘free’, unburdened and less stressed, irrespective of whether disclosure was partial or full. This contrasts with Comer (2000), who questioned whether disclosure had a positive impact on mental health.

This study, however, suggests that the benefits did not only relate to the release of stress associated with keeping the condition a secret. In addition, this study documents that there were a number of other more tangible health benefits for informants associated with disclosure. Importantly, the data from this study suggests that disclosure enabled health-seeking behaviour such as seeking treatment, keeping clinic appointments, adhering to ARVs, practising safe sex, and seeking support. Significantly, this study suggests that partial disclosure was instrumental in protecting unborn babies from contracting HIV by enabling their mothers to take ARVs to reduce the risk of mother to child transmission. It also

suggests that disclosing (especially to family members) and solicit support from them enabled the PLHA in this study to come to terms with their diagnosis.

This study suggests that the benefits of disclosure differ between partial and full disclosure. This differs with the study by Derlega et al. (2004), who do not distinguish between different forms of disclosure and with Norman et al. (2007) who distinguishes between different forms of disclosure, but does not look at the relevance of this in relation to benefits of disclosing. This study documents that disclosure does not have to be public, such as in Paxton's study, to be beneficially to PLHA. That said, an important finding relates to the limitations of the prevalent form of disclosure, the partial disclosure. The fact, that (sexual) partners were frequently excluded as confidantes meant that many PLHA in this study did not practice safe sex, which could have repercussions not only for the risk of infecting partners, but also for the health of PLHA. Where they lived with their partner, non-disclosure to partners had ramifications for the PLHA's health seeking behaviour such as seeking treatment, and adhering to ARVs. While most informants argued that they felt less stress after disclosure, it was clear that managing this very selective disclosure was difficult and stressful. Phumlani's case illustrates how difficult it was to manage partial disclosure when it excluded live-in-partners.

Another characteristic of the preferred way of disclosing was that it was a process that took many years. This correlates with Norman et al.'s (2007) study, which found that the first disclosure occurred a few years after diagnosis. In this township, the first disclosure frequently occurred 2-4 years after diagnosis, but in some cases only many years later. Consequently, the benefits of disclosure also had been deferred for years.

This study found that disclosure could also play a role in prevention as it facilitated the initiation of safe sex practices when disclosure was to partners. However, it found that this impact was limited by the fact that disclosure to partners was delayed or that many respondents did not disclose to partners at all. In line with the findings in Simbayi et al.'s study (2007), this qualitative study also found that non-disclosure to sexual partners was frequently linked to unsafe sex. Others made attempts at practising safe sex without disclosure, but this was difficult. Phumlani, for instance, did not think it possible to use condoms once she was married as she feared this would lead to an involuntary disclosure of her status.

Thus, disclosure can impact positively on the health and well-being of PLHA and facilitate initiation of safe sex practices. However, to realise the full benefit of disclosure, disclosure rates need to be improved and the very partial

disclosure, preferred by informants in this study, needs to shift to a full or more open disclosure. Furthermore, the benefits of full disclosure also depend on whether this occurs shortly after diagnosis or is delayed, following a partial disclosure. While a full disclosure that occurs shortly after diagnosis may have the most benefits, the findings in this study also suggest that the benefits related to partial disclosure depends both on when disclosure takes place and to whom. It points specifically to the importance of disclosure to sexual partners and people who live in the same household or are close to the HIV-positive person. To what extent a full disclosure is necessary to realise the full benefits of disclosure, or the benefits can be realised when disclosure includes partners and family members, is a question for further research.

The findings beg the question why disclosure rates were low in this township and why the preferred form of disclosure was the partial disclosure, characterised by being delayed and selective. Statistics on disclosure rates in South Africa are not available, but Norman et al.'s study (2007) provides figures for (partial) disclosure in the two communities they studied at 40 and 70 percent. There are no comparable data for this township. However, there were several indications that disclosure rates were very low, and considerably lower than in Norman et al.'s study. While the local clinic could not provide statistics on disclosure rates, they indicated that many patients refused to disclose even to one person to solicit the support of a 'treatment buddy'. The NGO Nakekela also observed that many PLHA were reluctant to disclose. Consequently, many rejected visits by the home carers as they feared that association with these carers (wearing T-shirts that said 'HIV-positive') would expose their status. This resulted in the NGO having to downscale its activities in this community.

This paper has identified stigma as a key factor in non-disclosure and in choosing partial and delayed disclosure. Full disclosure, on the other hand, was related to being able to resist and risk stigma. Those who disclosed fully did not experience stigma, such as Phelo, or were able to resist stigma such as Andile, Thandeka, and Nozuko. Those choosing partial disclosure dealt with stigma in two ways. Firstly, they managed disclosure by seeking out people who were unlikely to stigmatise and likely to be supportive. This was done through monitoring and sometimes testing people's attitudes. This finding supports the argument that a 'feeling out' of potential reactions preceded disclosure (Norman et al. 2007:1777).

However, this paper suggests that managing external stigma was not the only factor that facilitated partial disclosure. This research suggests that the way PLHA dealt with self-stigma influenced the choices they made about disclosure. The issue of self-stigmatisation is important because PLHA in this township

shared beliefs about HIV with the rest of the community - those they feared being stigmatised by. Thus, the paper challenges the distinction, prevalent in much literature on stigma between two groups – the stigmatised and the stigmatisers (see Campbell and Deacon, 2006). Rather, it suggests that there is a ‘thin’ line between the stigmatised and the stigmatisers in this township, a line which can easily be crossed. It was evident that all women in this study, prior to their own HIV-diagnosis, had harboured a belief that HIV is linked to ‘immoral’ female sexuality; the socio-cultural construction of AIDS as an ‘immoral’ disease is documented across many studies (Levine and Ross 2002, Grundlingh 1999, Delius and Glaser 2005). Similarly, the notion that women are vectors of HIV-transmission is also documented in qualitative research in South Africa (LeClerc-Madlala 2001, Jewkes et al. 2003).

The belief that HIV-status is linked to ‘immorality’ and personal responsibility led to self-stigmatisation and fear of external stigma. Before being able to disclose and risk stigma, PLHA had to reconfigure their identity in relation to stigma and the dichotomy of ‘guilty’/‘innocent’. How they dealt with self-stigmatisation was as important as how they managed the risk of external stigma. The fact that some women, notably Joyce, had begun to challenge the association between HIV as personal responsibility, without being willing to disclose and risk external stigma, suggests that dealing with self-stigma may be a first step in contemplating disclosure and risk external stigma. Andile’s full disclosure, described earlier, was facilitated by a change in how she felt about her HIV-status. More research on how PLHW deal with self-stigma and how this facilitates disclosure is needed.

Most PLHA in this study dealt with self-stigmatisation through an ‘insistence on innocence’ which repositioned them in relation to a ‘guilty’/‘innocent’ dichotomy without challenging the stigmatising beliefs behind this dichotomy, namely that HIV/AIDS is linked to personal responsibility and ‘immoral behaviour’. Two avenues were used to ‘insist on innocence’. The first was by insisting on limited knowledge about HIV/AIDS, such as Phelo and Gladys did. The second was through refuting that their HIV-status was a result of ‘immoral behaviour’.

The notion that stigma can be resisted and changed, which this study proposes, is supported by literature on stigma, such as Joffe (1999), Deacon (2005) and Parker and Aggleton (2003). The latter describe stigma as a social process that can change over time, and in different contexts. They suggest that while stigma is often internalized and accepted, leading to a spoiled identity, it can also be resisted and challenged. These authors theorized how identities change in relation to experiences of and resistance to stigma. They suggest three ‘types’ of

identities: legitimizing identities, which are introduced by the dominant institutions of a society, and lead to an acceptance/internalization of stigma; resistance identities, which are constructed by actors that are devalued and/or stigmatised by the logic of domination; and finally, project identities, which are formed by actors who use ‘cultural material’ available to them to build new identities that redefine their position in society and, in return, also challenge the overall structure of that society (Parker and Aggleton 2003).

While PLHA in this township who disclosed partially were able to create a ‘resistance identity’ - resisting a ‘spoiled’ identity - they rarely created ‘project identities’, where the stigmatizing beliefs are challenged publicly. Rather, their response remained channelled within a binary framework consisting of ‘innocent’ and ‘guilty’ ‘victims’. Through this they rejected responsibility for their condition, stigma and self-stigmatisation⁴ without challenging the ideological framework that underpin stigma.

In contrast, those who disclosed fully created ‘project identities’, where they challenged stigma publically and redefined their own position. Andile, for example, changed her view of HIV/AIDS as a shameful disease to a view that she was ‘proud of her status’. This enabled her to begin to speak up and finally to disclose fully.

The PLHA who disclosed fully either did not fear stigma or were able to publically challenge or risk stigma because they took on an ‘activist/advocate’ identity, convinced of the importance to raise awareness about HIV/AIDS. In many cases this was supported by formal activism. This finding is in line with Norman et al. (2007). Their study compared two communities in South Africa with very different disclosure rates. It concluded that the main factor that set the community with high disclosure rates apart from the one with low disclosure rates was the availability of institutional support, such as support groups, NGOs and hospitals. According to the authors, possibilities for activism, community involvement and for assuming a positive role model enabled public disclosure (Norman et al. 2007: 1780).

Institutional support and opportunity for activism did exist in this community. There were two support groups for HIV-positive and the TAC had a branch in the township. In South Africa, the TAC has played an important role in challenging stigma and, as Robins pointed out (2004), giving members a new

⁴ This distinction between ‘innocent’ and ‘responsible’ victims has defined the AIDS epidemic since its advent 25 years ago; with ‘innocent’ victims being haemophiliacs and children, and ‘guilty’ victims being homosexuals, prostitutes, drug users and ‘promiscuous’ adults.

sense of identity and belonging. Insisting on health as a human and a constitutional right, the TAC has challenged the prevailing discourse around health as a question of personal responsibility. Instead, it insists on the link between structural issues, disease risk and limited access to health care. The TAC has also challenged HIV stigma through challenging the notion of HIV as an ‘immoral’ disease, which can be blamed on the ill.

Why then were disclosure levels low and the preferred form of disclosure partial, in this township? Firstly, the local TAC branch differed from TAC in that its members did not disclose publicly, as encouraged by the TAC, but limited their disclosure to other TAC members. Thus, the local TAC may not facilitate disclosure and challenge stigma. Secondly, the township’s two support groups had limited reach. Although about 800 people were diagnosed with HIV, the two support groups had a total membership of 40. Thus, very few PLHA sought the support of these structures. Furthermore, they did not challenge HIV stigma significantly. It was clear that the support group I attended was very important for many members in that it provided them with information, advice, and support. But its collective challenge to stigma was limited. Rather, a struggle was taking place around disclosure; and the group as a whole shied away from full disclosure and confronting HIV-stigma. While I did not deal with the other support group, there were no visible signs that it publicly challenged HIV-stigma. Thus the impact on anti-stigma efforts and improving disclosure rates through these support groups, and through the local TAC branch, was limited.

This suggests that it is not only the presence of support groups and NGO’s that is of importance, but rather how they assist their members in dealing with stigma. This study points specifically to the importance of challenging the conceptualisation of HIV as a condition which the bearers bring unto themselves through ‘immorality’. One of the characteristics that differentiated partial and full disclosure was the way that HIV-positive dealt with this conceptualisation. Significantly, Phelo did not fear stigma because he did not associate HIV with personal responsibility and ‘immorality’, while Andile changed her view that only ‘prostitutes’ and ‘loose women’ could get HIV.

This resembles Campbell et al.’s (2005) argument for the importance of collective participation from stigmatised groups in combating stigma through what they call ‘critical thinking programs’. Such programmes would aim to “expose, confront, and resist the webs of significations and practices that sustain stigma and undermine the confidence of communities and individuals who might otherwise challenge it” (Campbell, Foulis, Maimane and Sibiya, 2005:814). This paper suggests that such programmes should focus on a challenge to the belief that HIV is an ‘immoral’ disease that the bearers are responsible for.

This research also points to a gendered aspect of disclosure and stigma. Despite women being stigmatised for ‘immoral’ behaviour, they seemed to find disclosure (both partial and full) easier or more preferable than men, who were reluctant to disclose. This represents a conundrum: if men are less likely to be stigmatised for ‘immoral’ behaviour, why are they much more reluctant to disclose? More research is needed to explore the gendered aspect of disclosure.

Conclusion

This paper has described a South African township with low disclosure levels. It has described two forms of disclosure: full and partial. It has suggested that the partial disclosure is a selective form of disclosure that is delayed by several years and often excluding sexual partners and live-in-partners. For this group, disclosure of HIV status was experienced as an ambiguous dilemma. On the one hand, disclosure was a means to the ‘cathartic’ release from the burden of hiding, being able to solicit support, and promoting both health and well-being; and, on the other, disclosure came with the fear of being stigmatised and discriminated against.

PLHA who disclosed partially managed the dilemma of disclosure through two approaches. The first consisted of seeking out people that were likely to be supportive and would not stigmatise. People were identified through monitoring or testing their attitudes to HIV. This enabled PLHA to minimize the risk of stigma, while achieving some of the benefits of disclosure. Through the second approach they addressed self-stigmatisation. This took the form of rejecting responsibility for their illness through ‘insisting on innocence’, either by claiming ignorance of HIV/AIDS or denying contracting the disease because of ‘immoral’ actions. These approaches enabled PLHA to reposition themselves in relation to the dichotomy of ‘guilty’ or ‘innocent’ victims, without challenging the ideological framework for stigma and the individualisation of blame.

The other form of disclosure was a full disclosure, characterised by the HIV-positive not attempting to hide his/her status and sometimes actively ‘displaying’ their status visibly through wearing HIV T-shirts. Full disclosure was rare. For some it occurred shortly after diagnosis. In these cases, self-stigma and fear of stigma was either absent or stigma was rejected and resisted. There was no fear of loss of support. For others, full disclosure followed a partial disclosure that had spanned years. In these cases, PLHA resisted and rejected both self-stigma and stigma. Full disclosure was motivated by a wish to raise awareness and

frequently linked to an activist identity that enabled individuals to resist or risk stigma.

Disclosure – both partial and full - was experienced as being beneficial to the health and well-being of PLHA. It made PLHA feel less stressed and enabled health-seeking behaviour such as taking ARVs correctly, seeking treatment, keeping clinic appointments, practicing safe sex and seeking support. It also helped some come to terms with their status. Significantly, it helped pregnant women to take ARVs, which reduce the risk of mother-to-child transmission.

However, the preferred partial disclosure which frequently excluded sexual partners and live-in-partners, as well as the delayed nature of disclosure, limited the potential benefit of disclosure amongst informants. Considerable energy was spent on managing the partial disclosure, reducing the impact of being unburdened and free of stress. Furthermore, health seeking behaviour, such as practicing safe sex, adhering to treatment, keeping clinic appointments and practicing safe sex was compromised when disclosure excluded partners. Because disclosure was delayed by several years, the benefits were also delayed or reduced. Exclusion of sexual partners as confidantes or delaying disclosure to sexual partners for years significantly limited the role disclosure had on prevention in this township.

Furthermore, this paper has argued that the full potential impact of HIV disclosure – both on PLHA health and well-being and prevention – can only be realised if the partial disclosure is changed to a full disclosure or a more open disclosure that includes sexual partners and people living in the same household, and if disclosure is not delayed significantly. This paper suggests that HIV stigma is a key factor informing the decision of whether and how to disclose. Changing the preferred way of disclosure requires that HIV stigma is addressed and challenged. It has suggested that prior to being able to risk or reject external stigma, PLHA need to confront self-stigma. How they deal with self-stigma is crucial in their decision of which form of disclosure to chose. Those that dealt with self-stigma through repositioning themselves in relation to a ‘guilty’/‘innocent’ dichotomy, without challenging the notion of HIV as a condition the bearer is responsible for, were unable to risk and resist stigma. On the other hand, those that refuted a link between personal responsibility and HIV were able to challenge self-stigma and subsequently risk and resist external stigma.

This paper has identified the conceptualisation of HIV as a condition that the bearers bring unto themselves through ‘immoral behaviour’ as a source for both HIV stigma and self-stigmatisation. PLHA feared being stigmatised because of

this understanding of HIV and shied away from disclosure to avoid stigma. It has suggested that HIV stigma largely goes unchallenged in this community because the local TAC branch and the two support groups have very limited reach, and because they do not challenge stigma or the notion of HIV as a condition people bring unto themselves through ‘immorality’.

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