

To tell or not to tell: Negotiating disclosure for people living with HIV on antiretroviral treatment in a South African setting

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Abstract

Disclosure of HIV status occurs for a variety of reasons and in various contexts, such as to sexual partners to enable safer sexual choices, to health-care workers to access treatment and care services and to family and community members to gain various forms of support. The reasons for disclosure or non-disclosure are shaped by the relationships, needs and circumstances of people living with HIV (PLHIV) at the time of disclosure. The purpose of this study was to investigate and describe the act and experience of disclosure in order to understand how these experiences of disclosure impact on the lives of PLHIV on antiretroviral (ARV) treatment and influence adherence to treatment. Using a qualitative research design, I conducted an ethnographic study at and through the referral clinic at the Tygerberg Hospital in Cape Town, South Africa. Ninety-three adult patients (75 women) participated in the study, 32 of whom were visited at home to conduct semi-structured in-depth interviews, and 61 of them participated in a cross-sectional study at the referral clinic using researcher-administered questionnaires. A general inductive approach was used to analyse the data. Participants in both arms of the study disclosed mainly to family members, then partners and then to friends and other persons; only five had not disclosed to anyone at all. In deciding to disclose or not, the author began to see how patients negotiated their disclosure. From weighing up other people's reactions, to being concerned about the effect of their disclosure on their disclosure targets, to concealing one's status to evade untoward negative reactions towards themselves. Further, negotiating one's disclosure is not only about to whom or how to disclose, it also means finding good opportunities to disclose or conceiving ways of hiding one's status and/or medication from others in order to enhance access and adherence to their ARV treatment. Perceived rather than actual stigma played an important role in decisions not to disclose. Nonetheless, HIV remains a highly stigmatising disease. The author suggests that both the gains in support and the evasion of negative reactions from the disclosure will continue to drive negotiation of disclosure of one's status in order for patients to access and remain adherent to their treatment. Thus, areas of disclosure and concealment as they influence one's adherence to treatment need to be investigated further to facilitate adherence to treatment.

Keywords: *stigma, discrimination, social, household, family, partners*

Résumé

Le partage du statut VIH a lieu pour diverses raisons et dans des contextes divers: avec les partenaires sexuels pour permettre des choix à moindre risque, avec les agents de santé pour accéder aux traitements et aux services de soins, et avec des membres de la famille et de la communauté pour obtenir diverses formes de soutien. Les motifs du partage ou du non-partage sont façonnés par les relations, les besoins et les circonstances des personnes vivant avec le VIH (PVVIH) au moment où elles partagent l'information. Le but de cette étude était d'étudier et de décrire l'acte et l'expérience du partage afin de comprendre l'impact de ces expériences sur la vie des PVVIH sous traitement antirétroviral (ARV) et leur influence sur l'observance au traitement. Utilisant un modèle de recherche qualitative j'ai mené une étude ethnographique dans et à partir de la clinique de référence de l'Hôpital Tygerberg au Cap, en Afrique du Sud. Quarante-deux patients adultes (75 femmes) ont participé à l'étude, parmi lesquels 32 ont été rencontrés chez eux pour des entretiens semi-structurés approfondis, et 61 ont participé à une étude transversale à la clinique par questionnaires administrés par des chercheurs. Une approche inductive globale a été utilisée pour analyser les données. Les participants dans des deux bras de l'étude ont partagé leur statut principalement avec les membres de leur famille, puis leurs partenaires, puis des amis et d'autres personnes, mais seulement 5 n'avaient pas divulgué leur statut VIH à qui que ce soit. L'auteur a commencé à percevoir comment les patients ont négocié leur communication soit en décidant de partager, soit en décidant de ne pas le faire : en anticipant les réactions des autres, en se préoccupant de l'effet de leur divulgation sur les personnes ciblées, en dissimulant leur statut pour échapper à des réactions négatives envers eux-mêmes. En outre, la négociation du partage de l'information ne concerne pas seulement le choix de la personne à qui communiquer ou de la manière de communiquer. Cela signifie aussi trouver de bonnes occasions pour annoncer son statut ou concevoir les moyens de le cacher et / ou de cacher les médicaments pour assurer son accès et son observance au traitement d'ARV. Perçue plutôt que réelle, la stigmatisation joue un rôle important dans la décision de ne pas partager. Néanmoins, le VIH reste une maladie très

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stigmatisant. L'auteur suggère que la recherche de soutien et delà volonté d'éviter des réactions négatives resteront des déterminants dans la négociation du partage de son statut VIH pour que les patients qui veulent accéder et rester adhérents à leur traitement. Ainsi, les zones de partage et de dissimulation, qui ont un impact sur l'observance, doivent être davantage étudiées pour favoriser l'adhésion au traitement.

Mots clés: *stigmatisation, discrimination, social, foyer, famille, partenaires*

Introduction

HIV/AIDS-related disclosure is defined as the sharing of an individual's HIV status with another person or organisation; an individual can disclose on his or her own, or someone can do it on his or her behalf, with or without the individual's consent (UNAIDS 2000). The intentions and outcomes of disclosure may be favourable or unfavourable (UNAIDS 2000).

Along with encouraging sexual partners to get tested and positive behaviour change among those infected with HIV, disclosure is touted by most international organisations and donors as the best means of preventing new infections and slowing the spread of HIV (Centre for Disease Control and Prevention (CDC) 2001; UNAIDS 2000). Still, many people living with HIV (PLHIV) prefer to keep their HIV status wholly concealed (Ware, Wyatt & Tugenberg 2006) or partially concealed from certain individuals such as partners (Medley, Garcia-Moreno, McGill & Maman 2004). However, Levy, Laska, Abelhauser, Delfraissy, Goujard, Boué, *et al.* (1999) noted that many HIV-positive individuals eventually disclose to someone at some point.

Disclosure is, in practice, a double-edged sword. While it can lead to improved access to voluntary counselling and testing (VCT), treatment and better social support, it can also close the very same channels to treatment access, and sever social support ties resulting in the loss of emotional, financial and physical support (Medley *et al.* 2004; Taraphdar, Dasgupta & Saha 2007).

The notion of stigma or having a stigmatising condition is not new. It was first defined by Goffman (1963) and further elaborated by Alonzo and Reynolds (1995) to take into account stigma and discrimination in HIV and AIDS illness trajectories. Studies by Herek and Capitanio (1993) and Herek, Capitanio and Widaman (2002) have described the pervasive and persistent nature of HIV/AIDS-related stigma in the USA over almost two decades, including after antiretroviral (ARV) treatment was available. Stigma and discrimination inhibit access to prevention, care and treatment services (Makoae, Portillo, Uys, Dlamini, Greeff, Chirwa, *et al.* 2009; Weiss & Ramakrishna 2001 in Campbell, Foulis, Maimane & Sibiyi 2005). A study by Genberg, Hlavka, Konda, Maman, Chariyalertsak, Chingono, *et al.* (2009) showed that people who did not know about HIV or AIDS, had never been tested for HIV and thus did not know their status, or who did not know about the existence or availability of ARVs, blamed PLHIV for their infection and isolated them. They also showed, however, that community programmes that promoted talking about HIV, AIDS and ARVs helped to reduce negative attitudes towards PLHIV.

Public disclosure of individual HIV-positive status has proven key to reducing stigma and discrimination (Norman, Chopra & Kadiyala 2007; Paxton 2002). The openness of some PLHIV have prompted individuals, communities and governments to take action on HIV/AIDS, including the establishment of proper prevention and care interventions (van Niekerk 2005), the dissemination of information about HIV/AIDS, and encouraging understanding towards people infected with HIV (Campbell *et al.* 2005; Gerbert, Sumser & Macguire 1991). In this way, public disclosure has also enabled communities to help shape positive behavioural changes (Muula & Mfutso-Bengo 2005), critical to establishing vital support and social acceptance of PLHIV (Cusick & Rhodes 1999).

Whilst stigma and discrimination have generally lessened over time, Makoae *et al.* (2009) show that those on treatment experienced higher levels of discrimination over time than those who were not on treatment. This was because it is more difficult to hide one's status when taking ARV treatment, due to regular clinical visits to the clinic, having one's blood drawn frequently, and having to take medication at specific times, twice daily for the rest of one's life. Thus, to avoid disclosure and keep their social support within the household, and social ties with friends and acquaintances, PLHIV will either delay or stop taking their ARVs (Makoae *et al.* 2009; Waddell & Messeri 2006). To the contrary, Stirratt, Remien, Smith, Copeland, Dolezal, Krieger, *et al.* (2006) found that individuals who disclosed had higher rates of adherence than those who had not.

Disclosure occurs for a variety of reasons and in various contexts: to sexual partners to enable safer sexual choices, to health-care workers to access treatment and care services; and to family and community members to gain various forms of support (Greene, Derlega, Yep & Petronio 2003 in Gaskins, Foster, Sowell, Lewis, Gardner & Parton 2011). The reasons for disclosure or non-disclosure are shaped by the (social) relationships, and the needs and circumstances of PLHIV at the time of disclosure (Bairan, Taylor, Blake, Akers, Sowell & Mendiola 2006; Gaskins *et al.* 2011; Ware *et al.* 2006). Mogensen (2010) notes that disclosing or concealing one's HIV status is a way to negotiate or access important objectives, as well as to control who knows about one's status.

Iwelunmor, Okoror and Airhihenbuwa (2009) pointed out that more research needs to be carried out to investigate the factors that influence the disclosure on the 'collective level', that is the disclosure to one's family and community. They hypothesise that this group may be important in determining whether or not individuals disclose (Iwelunmor *et al.* 2009). Studies show that attention to disclosure, as well as the reasons for disclosing,

the disclosure targets, and how disclosure is carried out are important for achieving both optimal PLHIV care and HIV prevention (Gaskins 2006; Gaskins *et al.* 2011).

Against this background, I set up this study to investigate how disclosure was carried out, to whom people disclosed, and their reasons for disclosing or not disclosing. I aimed to study this on the collective level, that is, from within the participant's family and community. Our results support findings from previous studies showing that patients disclosed to certain individuals for certain needs. One interesting and novel finding, however, was that despite concealing their status out of fear of being stigmatised or discriminated, many of our participants on treatment negotiated disclosure with the aim of enhancing both access and adherence to ARV treatment.

Research objectives

The findings reported in this article are part of a larger study to investigate how the care and support structures (care arrangements) for PLHIV on treatment had been or were being transformed with the advent of treatment, and how these transformations impacted on the adherence of PLHIV to their treatment. Four major themes were derived from the data, and below I report on one of these, the issue of disclosure. This study is incorporated in a project entitled: 'AIDS Medicines in Resource-Poor Settings: Learning from District Level Transformations in Health Cultures and Care Arrangements in Uganda and South Africa', set up at the AISSR of the University of Amsterdam, the Netherlands.

In the context of a survey, I asked research participants the following open-ended questions pertaining to disclosure:

- (1) To whom have you disclosed your HIV status and why?
- (2) How did you personally react to your diagnosis when your status was communicated with you?
- (3) How did those to whom you disclosed react?
- (4) Have you ever been treated badly as a result of disclosing your HIV status, or come across incidences of others being treated badly after those people disclosed?

Due to the open-endedness of the questions asked, the resulting data have been analysed using a qualitative rather than quantitative framework.

Study design and collection of data

The findings are based on 10 months of fieldwork conducted between January 2007 and May 2008, when ARV treatment was being rolled out and scaled up at the referral clinic at Tygerberg Hospital in Cape Town, South Africa. I used a qualitative descriptive research design, as described by Sandelowski (2000), to investigate and describe the act and experience of disclosure, with the specific aims of better understanding how experiences of disclosure impacted the lives of PLHIV on treatment and, and how it influenced adherence to treatment. I used a purposive sampling technique to recruit participants, and invited patients who were at least 3 months on treatment to participate. Of the more than 100 patients who were approached and invited to participate in the study, 32 agreed to participate including being interviewed

at their home settings rather than the clinic. Using semi-structured interviews, participants were visited at home at least once to conduct the interviews. An additional one to three visits were conducted with 12 of the 32 participants to complete the interviews, as well as continue observing participants in their home environments and their interactions with the people around them. Some household members with whom the participant felt comfortable to have present during the interview were also interviewed; this occurred with only seven of the participants. In the later phase, an extended research with another sample of patients to supplement the data obtained previously was conducted. Among the patients of the referral clinic, 61 agreed to participate in the survey. These researcher-administered semi-structured interviews were conducted at the clinic while patients waited to be seen by their doctor and lasted an average of 40 min. The survey questionnaire was adapted from the exit interviews for the Tanzania and Botswana country studies carried out by Hardon, Davey, Gerrits, Hodgkin, Irunde, Kgatlwane, *et al.* (2006), with the addition of care and disclosure research questions. Of the 93 patient participants, 32 were included in the follow-up arm of the study (female = 28; male = 4), and 61 were included in the cross-sectional arm (female = 47; male = 14).

In addition, I observed patients at the unit and conducted informal interviews with counsellors, nurses, support-group leaders and support-group members from Tygerberg and from other public health clinics rolling out ARV treatment in the surrounding areas. Using a purposeful sampling technique, I interviewed counsellors and support-group member and leaders who were/ worked with PLHIV on ARV treatment. I visited six facilities in Cape Town: three primary health-care centres and three day hospitals. I interviewed one to three counsellors at five of the facilities and two nurses from the sixth facility; I conducted two group discussions of five to eight support-group members, one at one facility and another that was church-based; and interviewed one to four support-group leaders at two facilities and at an NGO-run support-group in the area. I used topic guides that were adapted from the questionnaire guideline for key informant interviews as detailed by Hardon *et al.* (2006) to include open-ended questions that were derived from data already collected from the patient interviews. The topics included were: (a) knowledge and beliefs of patients about HIV, AIDS and ARVs; (b) perceptions, experiences and challenges of patients around disclosure; (c) perceptions, experiences with and challenges of stigma and discrimination for patients; and (d) support and care systems for PLHIV on treatment at in the home, at the health facility, and in general. Only issues relating to disclosure, stigma and discrimination and their influence on adherence to treatment are reported here. The remaining data on, from and about counsellors and support-group members are currently being written up separately to be reported elsewhere. Due to the open-ended nature of the questions, the data have been analysed using the qualitative method detailed below.

Depending on the patient's preference interviews were conducted in Afrikaans, Xhosa or English. Most interviews were recorded; written notes were made for the few who declined to be audio recorded. The recordings and notes were simultaneously translated into English and transcribed, and stored as encoded

documents in a password-protected folder accessible only to the researcher. The audio tapes were stored in a locked cabinet in the researcher's office.

Study site

The study was conducted at and through the Infectious Diseases Unit of the Tygerberg Hospital. This is an outpatient facility providing care and treatment of infectious diseases for patients referred to the facility by their public-sector primary health-care centre. However, mostly HIV-infected patients initiating or established on ARV treatment were seen in the unit, whilst TB patients were only attended to if they were also undergoing treatment for HIV, or experiencing complications with their TB treatment. The ARV treatment rollout programme at Tygerberg is a government-run programme that began in January 2004. By the end of November 2004, approximately 1000 patients were receiving ARV treatment at the unit. Tygerberg Hospital was one of only four sites in the Western Cape accredited to rollout ARV treatment in 2004, and thus the patient loads were quite high at the beginning of the programme. In January 2008, about 796 patients were receiving their ARV treatment through the unit, with 24 new patients starting treatment that month. As more sites were accredited, patients stably established on treatment were referred to other facilities. In government-run ARV treatment programmes, all ARV medicines were provided free of charge to all patients accessing the unit, however, some costs or fees were charged for making use of the services at the hospital, which were on a sliding scale to ensure that those who were unable to pay the fees would still have access to the free drugs. This study focuses only on ARV treatment.

Ethical considerations

Ethical approval was obtained from the University of Stellenbosch's Centre for Human Research Ethics Committee. For the following-up of patients at their homes, only patients who agreed to be visited at home were recruited for the study. Informed consent was obtained written and/or verbally from all participants before commencement with an interview. All patient participants were assured anonymity, and thus only pseudonyms are used. All participants were made aware that the study findings would be written up for a research report using the pseudonyms.

Data analysis

I used a general inductive approach to analyse the data (see Thomas 2006). This approach permits research findings to emerge from the raw data without being constrained by preconceptions, theories or hypotheses during the collection or analysis of data (Thomas 2006). I manually analysed the data using a method outlined by La Pelle (2004) that, with aspects of the stages of coding process from Hahn (2008), enabled the use of Microsoft Word to code and analyse the data. Briefly, I read the transcripts line-by-line to identify pieces of text that dealt with disclosure of one's status, disclosure-related discrimination or being treated badly, reactions to disclosure, and impact or influence of disclosure or use of treatment on the participant's adherence to treatment. These pieces of texts were cut and pasted into a new document in a table format with extra columns to add in the themes and/or categories as I went through the selected texts

again. I then reduced the categories to remove overlaps or non-relevant material, by grouping similar codes together. I then built a model by looking for sub-topics, and linked categories together that had similar meanings. These sub-topics and linked categories were used to report the results in this article.

Results

Socio-demographic characteristics of the participants

Table 1 presents demographic data for the sample ($N = 93$). One male for every five females were recruited onto the study, hence

Table 1. Demographic characteristics of the participants living with HIV/AIDS and on ARV treatment.

Characteristic	Survey participants	Follow-up participants	Total
Total number of participants	61	32	93
Gender			
Female	47	28	75
Male	14	4	18
Race			
Black	43	19	62
Coloured	17	11	28
Indian	1	1	2
White	0	1	1
Age (years)			
20–29	10	10	20
30–39	31	14	45
40–49	17	6	23
50–59	3	2	5
Education level			
Primary school (never finished)	14 (10)	10 (6)	24 (20)
Secondary school (never finished)	38 (27)	19 (15)	57 (42)
Tertiary education (never finished)	9 (0)	3 (1)	12 (1)
Marital status	Not measured		
Single/never married		9	9 ($n = 32$)
Married		12	12 ($n = 32$)
Widowed		1	1 ($n = 32$)
Separated/divorced		5	5 ($n = 32$)
Cohabiting		5	5 ($n = 32$)
Children	Not measured		
Yes		26	26 ($n = 32$)
No		6	6 ($n = 32$)

the data are skewed towards women and their viewpoints. Two-thirds of the participants were black, and almost half of the participants were in their 30s. Whilst a quarter of the participants had only had primary school education or less, around two-thirds of the participants had started secondary school with three-quarters of these not finishing it. Almost two-fifths of the follow-up participants were married, whilst less than one-third were single. Four-fifths of the follow-up participants had children. Marital status and children were not evaluated for the survey participants.

To whom disclosed or not disclosed

Participants disclosed to certain people for certain needs. Even those participants who claimed they had not disclosed to anyone when asked directly, responded to different questions that they did indeed disclose in specific circumstances, for example, when they had required care after falling ill from an AIDS-related illness, or to a TB directly observed treatment (DOT) supporter who made home visits. This may suggest that when asked about disclosure, people differentiate between publicly disclosing for the sake of making one's status generally known and disclosing in specific need-based circumstances.

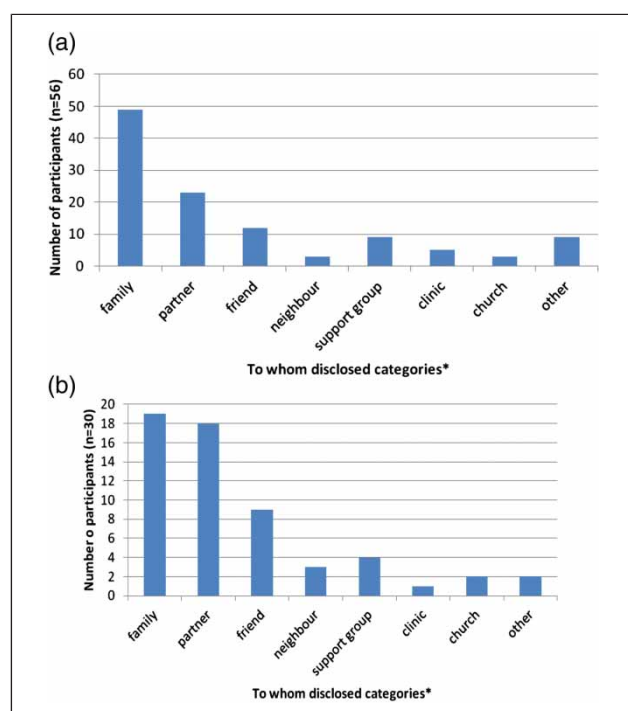


Fig. 1. (a, b) are diagrammatic representations of the disclosure targets for participants of the cross-sectional survey and follow-up visits, respectively. Clinic represents health-care workers, including counsellors and DOT supporters. Church includes priests/pastors and/or congregation. Other refers to anyone, for example work colleagues, parole/jail officers, other HIV-positive people that the participants encountered or people in their neighbourhood. Three participants had not disclosed to anyone, one participant said that they just prayed, and one participant had not completed this question, whilst two participants reported not having disclosed to anyone (not included in (a, b), respectively).

As can be seen from Fig. 1(a, b), the most common targets of disclosure were family members, a category that included (grand) parents, siblings, children, in-laws, cousins, aunts and uncles, followed by disclosure to partners, i.e. girl-/boyfriends, husbands or wives, and then to friends and other persons. Participants from the follow-up arm of the study, disclosed almost as often to partners as they did to family members, whilst survey participants were much more likely to disclose to family than to partners and friends. Five participants had not disclosed to anyone.

It is likely that follow-up participants are a more biased sample with respect to disclosure than the survey participants. First, I have a majority female sample ($n = 75$). All the men in the follow-up arm of the study had disclosed to their (ex-) girlfriends and wives. The participants in the follow-up arm of the study agreed to have the interviews conducted at their homes suggesting that they were more likely to disclose to many of their family members and to partners than the other (survey) participants. This is supported by the observation that most participants who agreed to participate in the survey explicitly did not want to be interviewed outside of the clinic (see study limitations), and that I also had follow-up participants pulling out of the study when I arrived at their homes and someone else, family members, neighbours or friends, had come to stay or visit. These participants then declined to answer any questions and asked the researcher to leave. Thus, I propose that the more representational study results are from the survey participants who disclosed mainly to family and only half as much to partners.

Reasons for disclosing or not disclosing

For both the survey participants as well as those visited at home who did not disclose, participants reported that they saw no reason to disclose. They did not find it necessary or they simply did not want to:

No I don't want to and I don't have a reason for that. (Sonia, survey participant)

Some patients noted that their family was far away and thus they had not disclosed to them as yet. Others, especially those who had rented a room in a house away from family, said they did not know the people around them well enough to disclose. Others reported that they did not think that disclosure would result in anyone helping them (cf. Moyer 2012).

A few participants reported they were not ready to disclose or were afraid of disclosing. They did not trust anyone enough and feared that if they did disclose, those who learned of their status would shout at them or berate them publicly when in a fight or drunk. Fears of being rejected, cast out or deserted by the people around them were also reasons why some did not disclose. Monette, who had disclosed to her grandmother and her children who were living with their grandmother, said:

Only my loves, the kids and my granny (know about my status). The people I stay with will kick me into the street if they must find out. (Monette, follow-up participant)

Some participants felt that many people were misinformed or ignorant about HIV and AIDS, which would lead to them being rejected, treated badly or stigmatised if they were to disclose. Still others did not want to disclose to particular individuals who they thought would be likely to make fun of them. One participant reported having been made fun of when she had been ill with an AIDS-related illness.

Because of the stigma attached to HIV and AIDS, participants did not easily trust that others would be supportive. One participant summarised:

I find it difficult to disclose because you have to be close to and build trust first with the person you have to disclose to. If you do not trust that person, you will have that fear because this is your private life and (your status) is confidential. (Nelly, follow-up participant)

Other participants had not disclosed to certain people out of concern for those people. They felt that their disclosure targets were too old or too sick to be burdened by the disclosure, or simply that as participant was the breadwinner, the disclosure targets would worry that they, the participant, would die and nobody would be there to take care of them.

I haven't disclosed to my mother. She is old and I think that she will think that this (HIV) is deadly and that I'm dying. So I don't want to tell her. (Charmaine, survey participant)

I haven't disclosed to my father. He is too sick and this will make him die sooner if I were to tell him. (Paul, follow-up participant)

Participants weighed up the costs and benefits, not just for themselves, but on behalf of their disclosure targets as well.

Personal reactions to disclosing

The participants also explained how they had felt when they had disclosed. Some had been 'relieved' and had 'felt better' after disclosing. They felt that they had nothing to hide anymore and felt they had a load taken off them. They felt free.

Although some participants did not have a problem disclosing, whether or not they received a positive or negative response, others were doubtful, worried or even scared of disclosing. A few participants had had no choice disclosing their status:

I was sick in hospital. It was not out of choice. The doctors said I should tell them. (Hilda, survey participant)

A few others had been too ill to tell anybody about their status, and the doctors or counsellors had disclosed their status to their families on their behalf, believing that the participant would die and their families would not know why.

Some participants reported they were never able to overcome their initial reactions of shock, disbelief and being heartbroken on hearing they were HIV positive and thus did not feel good about disclosing. Others did not find it easy to disclose and had

delayed until they had become visibly ill when their bodies either forced them to disclose or betrayed them to suspecting caretakers.

Other people's reactions to the disclosure

When participants eventually disclosed, others' reactions varied considerably. Some disclosure targets had already suspected, or already knew that the participant was HIV positive and consequently the participant did not see a change in attitude or relation to them.

Often disclosure targets did not react negatively to the disclosure event. Some even used it as an opportunity to disclose that they, too, were HIV positive.

However, some disclosure targets did experience shock and were heartbroken. Some were so shocked with the news they were unable to cope and even stopped talking to or interacting with the participant for some time, usually a few months. Even worse for some participants, disclosure came at a personal cost:

He (the children's father) is the one I disclosed to, but after I gave birth, he left me and said he doesn't have HIV. Even now he's not taking his ARVs. (Cecilia, survey participant)

A few men rejected and abandoned their female partners when they disclosed and, like Cecilia's partner, they often claimed they were not HIV positive and used that as justification for leaving. Most women participants reported this could not be true because they had not had any other partner, or had been HIV-free prior to the start of the relationship and remained monogamous within it. Like Angie, who had a child out a previous relationship, and was now married to her second partner, discovered her status shortly after falling pregnant from the second partner. She had been HIV negative when she had given birth the first time (Angie, follow-up participant).

Consequences of a disclosure

Many participants received support from family members, friends, neighbours, partners, and other HIV-positive individuals they met at support groups or the clinic. This support usually involved advice giving, for instance when they were experiencing problems or about their children. It could also be financial support to help the participant get to the clinic to have their treatment, or to remind and encourage the participant to take their treatment, so as to stay strong and be around for their children. Other support came in the form of physically caring for ill participants.

Two-fifths of the participants, however, felt that they had not received support since the disclosure, and had in fact been made fun of, been excluded or rejected. They did not feel that they had gained any support from their disclosure targets and that they continued to be left on their own and were often even ignored.

Stigma and discrimination

Thus far, all references to stigma and discrimination were of perceived stigma, that is, the participants were too afraid to disclose

because they feared that they would be rejected or publicly berated if their HIV status were to become known. In this section, I discuss experienced stigma, and present findings regarding participants' personal experiences with as well as their personal knowledge of others' experience of stigma and discrimination as a result of their HIV status being known.

Participants reported that they had experienced discrimination from health-care staff, from family members, partners, and neighbours and acquaintances.

My sister is also HIV positive; when she was sick, the nurse at [name of day hospital] didn't speak nicely to her and the doctor told her that even if she starts her ART she will die anyway. (Charmaine, survey participant)

Participants believed they were discriminated against because many in society thought that being HIV positive meant they had been sleeping around, lived a fast life (been reckless), or had many partners, actions that were frowned upon, especially by the church.

Others reported that they felt they had been rejected by those who feared being infected by the HIV-positive individual. People's ignorance about means of HIV transmission and fear of death led them to separate their utensils from PLHIV and avoid touching them or anything they used. Surprisingly, a few participants had found themselves doing or feeling the same about other HIV-infected persons, such as separating other's utensils, avoid using the same toilet or bath of an HIV-infected person, etc., but said that they would feel bad if someone did the same to them.

Negotiating one's disclosure for various goals

Whilst the obvious reason for negotiating disclosure is to avoid being discriminated or treated badly by others, participants were also careful to negotiate to whom they disclosed and how they disclosed.

A participant recounts how she managed to disclose to her partner. When she had TB and was losing weight, she used the opportunity to disclose to her partner when he asked about it:

No, I kept quiet although he saw that I'm losing weight. I decided to tell him that I have TB and he was asking me if I have tested for HIV as well. This is when I got the chance to disclose my status to him. It was not easy because I did not know how he was going to react. All I was thinking was that he will leave me. (Agnes, follow-up participant)

Her partner did not leave her, in fact they eventually married. However, they both decided that she should not disclose to anyone else, especially not to his family. When she had been ill, he had helped, whilst members of his family gossiped about her saying that she was infected and was going to die of AIDS. However, this also meant that when they visited his family home-stead in the Eastern Cape, she had to hide her ARVs to make sure no one saw her using them for fear they would reject her and make it difficult for her marriage and their children. In her

case, she reported that she took her medication secretly whilst in their company so as not to jeopardise her adherence.

Another participant, Edna (follow-up participant) had also used her AIDS-related illness as an opportunity to disclose to her husband. She had shingles, and when he had asked about them, she decided to disclose. Unfortunately, he rejected her, told her that she would die alone and he would marry another wife. After 2 weeks he moved his things out and never came back, leaving her and the children penniless and without food on the table. Edna was illiterate and unemployed and had to rely on her sister, and the small child-care grant for her youngest child to make ends meet.

Some participants were unable to negotiate disclosure in the way they would have liked. Marko (survey participant) was so ill from TB that he was taken to hospital and admitted. People around him were aware of this, and thus he had nothing to hide. Because of his severe case of TB, which is itself a stigmatised disease, and because TB is often associated with HIV, people suspected he was HIV positive.

Other participants went to great lengths to access a hospital or clinic far away from their home to remain anonymous and use HIV and ARV services without being seen by family members or neighbours, as would be the case if they accessed these services from their local clinic. Ellen (follow-up participant), who had been asked to consider transferring to a local clinic, discussed over several weeks with me how she was going to access ARV treatment services from a day hospital in a neighbouring suburb because she did not want to go to the clinic in her neighbourhood. Although she spoke freely about her status at home, she and her family were trying to keep her status hidden from neighbours and acquaintances to prevent the whole area knowing. This was complicated by the fact that all clinics and day hospitals required proof of residence when registering for services and those who did not live in the area were not permitted to use the services. She eventually found a friend, a fellow HIV-positive patient from the referral clinic, who was willing to allow her to use her address to sign up at the day hospital of her choice, thus demonstrating the lengths people will go to hide their status from select individuals and groups.

For Joanna (follow-up participant), all five of her siblings knew her status, and her family was quite close. However, Joanna was uncomfortable about taking her medication in front of other people, and whenever her sister and brother-in-law asked them to go out with them, she hesitated and usually declined. She felt embarrassed taking her medication in front of other people:

I don't want to drink my pills at other people's places, because they look, they really look. If I'm with them (my sister and her husband), I'll just say wait, I must drink my pills now. They (other people) think that I'm sick, but it's really none of their business anyway. But they don't really need to know because they might treat a person differently. People don't think the same . . . they don't want you to use their toilet and stuff. I tell my sister they can go, I will rather stay at home. Then my brother-in-law would say

'no, don't be like that sister-in-law, come with'. But I don't like to take my pills at other people's places. (Joanna, follow-up participant)

For Joanna, and for a few other participants, just having someone see them take their medication was enough to stop them from interacting socially with others, to avoid going out or visiting family and friends who were not aware of their status. However, some participants who did go out and visit family, only did so if they could take their medication without others seeing, or if they could step out or return home in time to take their medication without being seen.

Discussion

The results in this study show that all but five of the participants had disclosed their HIV status to at least one other person. This is similar to studies by Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, *et al.* (2006), Deribe, Woldemichael, Wondafresh, Haile and Amberbir (2008), Deribe, Woldemichael, Njau and Yakob (2009), Medley, Kennedy, Lunyolo and Sweat (2009), Gari, Habte and Markos (2010) and Ssali, Atuyambe, Tumwine, Segujja, Nekesa, Nannungi, *et al.* (2010). In the results, a diagram showed the preferences for disclosure targets, the persons to whom the participants had disclosed. Many participants disclosed to family and then partners and then friends, before any other groups or individuals. Studies by Mathews, Kuhn, Fransman, Hussey and Dikweni (1999), Skogmar *et al.* (2006), Deribe *et al.* (2008), Deribe *et al.* (2009), Kadowa and Nuwaha (2009), Gari *et al.* (2010) and Ssali *et al.* (2010) show similar results. Significantly, Skogmar *et al.* (2006) and Ssali *et al.* (2010) noted that their respondents had disclosed mostly to family members (collectively) and partners more than to friends and other persons. Mathews *et al.* (1999), Issiaka, Cartoux, Ky-Zebro, Tiendrebéogo, Meda, Dabis, *et al.* (2001), Gari *et al.* (2010) and Deribe *et al.* (2008) reported that their respondents had disclosed more frequently to sexual partners than to family members or other significant individuals in their lives. This is not uncommon as partners and family members provided the most moral and social support after being disclosed to (Skogmar *et al.* 2006). Disclosure to partners (a) increased the individual's closeness with their partner through support and assurance which also lowered their level of depression; (b) helped to protect from HIV infection or prevent HIV transmission; and (c) helped the other partner prepare for the future such as looking after children should the one partner die from AIDS (Deribe *et al.* 2008; Skogmar *et al.* 2006; Ssali *et al.* 2010).

Next, I looked at the reasons for disclosing or not disclosing one's status, and already herein I begin to see patients negotiating their disclosure. Participants weighed up other people's reactions, were concerned about how the disclosure would impact their targets, and even concealed their status to prevent being rejected by partners or treated badly by those around them. If support was to be given, then the patients would disclose. Cusick and Rhodes (1999), Issiaka *et al.* (2001), Medley *et al.* (2004) Deribe *et al.* (2008), Kadowa and Nuwaha (2009) and Gaskins *et al.* (2011) had similar findings. A few other participants had no choice because being sick or being on treatment already exposed or disclosed one's status, similar to findings by Makoe *et al.* (2009).

Ssali *et al.* (2010) noted that respondents disclosed to explain changes in appearance and behaviour to family and friends more than to partners/spouse due to the length of time of the relationship. However, two participants in my study specifically explained these changes to their spouse/partner, which further implies negotiating disclosure of their HIV status.

Studies by Issiaka *et al.* (2001), Deribe *et al.* (2009), Kadowa and Nuwaha (2009), Gari *et al.* (2010), and Ssali *et al.* (2010) show that fear of negative reactions such as rejection, abandonment, violence, stigma and discrimination, losing one's job, being blamed for immorality/infidelity, but also not wanting to worry others, were the main reasons given for not disclosing one's status to other people/groups. In this study, mostly perceived stigma from other people played a greater role in why participants did not disclose to certain people, more than the actual negative or untoward reactions that participants actually faced. Perhaps this is why, when they weighed up the costs and benefits of disclosing, or choosing certain individuals to disclose to and not others, they did so to mitigate these bad reactions, and thus minimise the actual stigma and discrimination that they would receive. Almeleh (2006) found that his study participants weighed up the perceived negative responses towards one's HIV-positive status disclosure with the potential positive support that certain individuals could offer them, and ultimately chose to disclose to persons they trusted, who were of value to them and from whom very little or no negative reactions or outcomes were expected to result from the disclosure.

A study by Wouters, van Loon, van Rensburg and Meulemans (2009) demonstrated that the community support and continuous encouragement to disclose given by community health workers and HIV support-groups to PLHIV on ARV treatment tipped the negotiation/consideration scales in favour of disclosure to family members. They suggested that if patients received more social support, they encountered less stigma which promoted more status disclosure, and this community support became an alternative form of support if disclosure to family members leads to unfavourable consequences (Wouters *et al.* 2009). Despite the low incidence of actual stigma and discrimination and bad reactions experienced by the participants in the study, HIV is still a highly stigmatised and stigmatising disease. Thus, disclosure of HIV status will remain a complex issue negotiated in a maze of transforming social and family ties (Bairan *et al.* 2006). Both Wouters *et al.* (2009) and Ouédraogo, Ouédraogo, Ouédraogo, Soubeiga and Kyelem (2005) note that more public education and community support is needed to increase acceptance and disclosure of PLHIV to family and friends.

Brou, Djohan, Becquet, Allou, Ekouevi, Viho, *et al.* (2007), Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo (2007) and Nebié, Meda, Leroy, Mandelbrot, Yaro, Sombié, *et al.* (2001) found that their study respondents chose specific moments to disclose to sexual partners such as to access prevention of mother to child transmission (PMTCT) programmes, selecting an alternate infant feeding method, making safer reproductive choices for the mother and the infant, and to prevent HIV transmission and promote testing. Findings in my study showed

how the participants further negotiated their disclosure to others by not revealing their status, choosing certain moments to disclose, or avoided going out in order not to have to keep explaining their medication or to disclose their status and to mitigate bad reactions. Unlike previous studies that reported on disclosure for the purpose of preventing HIV transmission, this study's findings demonstrate negotiation of disclosure by PLHIV on treatment who wanted to continue to take their medication and remain adherent to their treatment, despite their family or the living arrangements they found themselves in.

Skogmar *et al.* (2006), Deribe *et al.* (2008), Medley *et al.* (2009), and Ssali *et al.* (2010) investigated issues of disclosure with individuals taking ARV treatment. Medley *et al.* (2009) note that taking ARV treatment helped patients to cope with HIV status as ARV treatment returned them to a healthy state thereby hiding their HIV signs and symptoms from others and thus enabled them to conceal their HIV status. Skogmar *et al.* (2006) found no significant correlation between use of ARV treatment and disclosure.

Participants in the current study had to find ways to remain adherent to their treatment whether or not they disclosed their status to others. This included avoiding or planning visits to family or going out around their medication to avoid disclosure (Skogmar *et al.* 2006). This is similar to the results by Skhosana, Struthers, Gray and McIntyre (2006) and Klitzman, Kirshenbaum, Dodge, Remien, Ehrhardt, Johnson, *et al.* (2004) who described how their respondents adjusted their lifestyles (such as avoid going out), lied about their treatment (such as treatment was for TB) or their status (such as claiming to have a different illness) to avoid being disclosed. The current study demonstrates how these tactics were employed to enable participants to remain adherent to their treatment when household or other circumstances were not conducive to disclosure of status or use of medication. This was unlike the study by Skhosana *et al.* (2006) wherein respondents skipped their treatment to avoid disclosure in order to maintain certain family and social ties.

The use of ARV treatment facilitates treatment of and thus the concealment of the tell-tale signs of AIDS disease, and hence aids in the concealing or not disclosing of one's status (Mogensen 2010). In this study, two participants stated that because they looked good, with the use of ARV treatment, when they had disclosed to family or other patients in the clinic waiting room to encourage HIV testing and knowledge of own status, the disclosure targets had thought that the participant was joking or had been 'bought' by the clinic to say that they were HIV positive to get patients to test. Hence, there remains a need to further investigate these spaces of disclosure and concealment and to examine the impact that the use of ARV treatment has on: (a) driving HIV underground; (b) hiding one's status; (c) increasing denial; (d) influence on stigma and discrimination; or (e) encouraging access to VCT and treatment. Skogmar *et al.* (2006) also suggested that disclosure incidences could be influenced by, namely (a) increased disclosure by PLHIV on treatment who felt well and experienced no stigma, (b) decreased disclosure by PLHIV on treatment who felt well but saw no reason to disclose, as well as

(c) no change in (non-)disclosure despite being on treatment. Hence negotiating one's disclosure was not only about who to tell and how to tell, it also meant finding a good opportunity to tell, or even conceiving ways of hiding one's status and use of treatment from others, in order to enhance access and adherence to treatment.

Study limitations

I set out to investigate how disclosure was carried out, to whom the participants disclosed and what their reasons for disclosing or not disclosing their status to others were, by studying this at the collective level, that is, from within the participant's family and community. However, access to and the retention of participants in the study proved difficult. Stigma and discrimination played a much greater role for all the participants who refused to participate or who agreed to participate but never showed up for appointments, declined continuing with the interview if someone came to visit them, because they did not want those around them to know. This resulted in far less patients participating in the survey and fewer consistent home visits than planned. As it was not possible to endlessly recruit patients until the desired quota was attained, I stuck to those I had and could visit at their homes.

Another study limitation was the lack of space at the referral clinic, and as such I was unable to always find a quiet, private space for any length of time to conduct the interview to its completion or to flesh out answers for open-ended questions. Questionnaires were rushed through and interviews were carried out in unused corridors or staff rooms, if vacant or unoccupied by other researchers or staff at that time or day. Also, many patients who agreed to take part in the survey explicitly did not want to be followed up at home or elsewhere outside of the clinic, hence sensitive topics and space constraints of this nature should be considered carefully before conducting similar studies.

Conclusion

The results show personal negotiations of disclosure in order to access and adhere to ARV treatment. Receiving care, getting the burden off one's shoulders, having someone else know about their illness, reminding them and helping them to adhere to their treatment, were some of the positive responses to disclosure of HIV status. Still, others did not disclose, chose to disclose only to other HIV-positive people on treatment, kept their status secret to avoid bad reactions or being abandoned by partners and family, whilst taking their medications secretly or foregoing social activities in order to remain adherent to their treatment. Patients negotiate their status disclosure to facilitate adherence to their treatment, whilst also maintaining social ties or relationships with others, be it family, partners or friends, as well as mitigating stigma and discrimination. The effect and reach of stigma and discrimination should not be underestimated or ignored by all linked in the web of social ties of the patient, especially those encouraging disclosure, such as health-care workers, counsellors, activists and support-group leaders. Disclosure is not a linear or unilateral process, but rather one that takes place over time and changes with the circumstances and needs of the discloser as well as their relationship to the disclosure target.

Gaskins (2006) has suggested that patients could benefit from being counselled in skills to carry out a disclosure. However, it is important to note that the need, reasons and circumstances that determine disclosure of one's status be appraised, along with the appropriateness of one's disclosure target for the disclosure, before a disclosure is encouraged. Additionally, disclosure targets require time to accept and adjust to the disclosure themselves, as it is not always easy for them to receive the disclosure. Future studies should assess whether providing skills to patients on how to disclose to others or having a counsellor support the patient during the disclosure facilitates positive outcomes to the disclosure and better adherence to treatment.

More studies are needed that look beyond disclosure for the purposes for HIV prevention. This article has suggested that there are needs, circumstances and relationships at play in an HIV-positive person's life that hinder or drive disclosure that in turn hinders or drives adherence to one's treatment, and these need to be investigated further.

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