‘My biggest fear was that people would reject me once they knew my status…’:

stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg,

South Africa

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Abstract

Stigma is not a new concept; however, it remains highly significant in the context of HIV/AIDS in South Africa. There is wide consensus that HIV/AIDS-related stigma compromises the well-being of people living with the disease. This paper is part of a larger study that seeks to understand the social and cultural complexity related to the provision and outcomes of antiretroviral therapy (ART) in South Africa. It explores and analyses how patients on ART perceived and experienced stigma and how it has shaped their behaviour towards, as well as their understanding of the epidemic. The data have been collected by means of in-depth face-to-face interviews, conducted between June and November 2007, with a sample of 44 patients in an HIV/AIDS clinic in a resource-limited setting in Johannesburg, South Africa. The findings reveal that the level of felt and anticipated stigma is intense and affects all dimensions of living with HIV/AIDS, particularly disclosure and treatment. Stigma permeates the experience of HIV-positive people on ART who participated in this study. The intensity of HIV/AIDS-related stigma can threaten to compromise the value of ART, thus impacting on the daily lives of people living with HIV/AIDS (PLWHA). This study suggests that three decades into the epidemic, stigmatisation remains a core feature of the patient experience of HIV/AIDS. In the clinic in which this research was conducted, HIV/AIDS was regarded as a chronic condition increasingly manageable by ongoing access to ART. However, this approach was not shared by many family members, neighbours and employers who held highly stigmatised views.

Keywords: antiretroviral therapy, disclosure, HIV/AIDS, South Africa, stigma

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Introduction

Stigma is not a new concept; however, it remains highly significant in the context of HIV/AIDS in South Africa. The impact of stigma on the epidemic and on people living with HIV/AIDS (PLWHA) has been widely discussed and analysed in South Africa (Reid & Walker 2003, Campbell et al. 2005, Steinberg 2008). There is consensus that HIV/AIDS-related stigma compromises the well-being of people living with the disease. Stigmatised individuals suffer discrimination that can lead to loss of employment and housing, estrangement from family and society, increased risk of physical violence and even murder (Walker et al. 2004).

From a public health perspective, HIV/AIDS-related stigma also fuels new HIV infections because it can deter people from getting tested, make them less likely to acknowledge their risk of infection and discourage those who are HIV-positive from discussing their HIV status with their sexual partners and others (HRSA 2003). It may also prevent them from accessing much needed antiretroviral therapy (ART) (Mahajan et al. 2008).
Goffman (1963) described stigma as ‘an attribute that is deeply discrediting within a particular social interaction’ (p. 3). His explanation of stigma focuses on the public’s attitude towards a person who possesses an attribute that falls short of societal expectations. Goffman identifies three distinct types of stigma:

1. Stigmas of the body (such as blemishes or deformities);
2. Stigmas of character (e.g. the people with mental health problems or the criminal); and
3. Stigmas associated with social collectivities (‘racial’ or tribal), all of which he stresses are socially, culturally and historically variable (Gabe et al. 2004).

Juxtaposing HIV/AIDS against Goffman’s three potential attributes of stigma it is evident that more than one attribute, and often all three, might apply at the same time – increasing the severity and complexity of stigma related attitudes and behaviour in comparison to other stigmatised conditions where only one of the attributes applies. According to Simbayi et al. (2007), HIV/AIDS is perhaps the most stigmatised medical condition in the world.

Although the concept of stigma has been applied to a myriad of social and medical circumstances (Link & Phelan 2001), Goffman’s ideas are a common thread in most of the published research and provide the theoretical underpinnings for much of the literature on stigma and stereotyping (Yang et al. 2007). According to Goffman and other scholars, diseases associated with the highest degree of stigma share common attributes:

- The disease is progressive and incurable;
- The disease is not well understood among the public; and
- The symptoms cannot be concealed.

HIV/AIDS fits the profile of a condition that carries a high level of stigmatisation (Herek 1999, Yang et al. 2007). First, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions. Second, although AIDS is treatable, it is nevertheless a progressive, incurable disease, and more so in countries like South Africa where only approximately 28% of those in need of treatment have access to it (WHO 2008). Third, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease (Moler & Erstad 2007). Finally, as HIV infection is asymptomatic it can often be concealed, however, the symptoms of AIDS-related illnesses cannot – these symptoms may be considered repulsive, ugly and disruptive to social interaction (Herek 2002). The HIV/AIDS body is a highly stigmatised body.

Scambler (1989, 2004) makes a useful distinction between ‘felt’ and ‘enacted’ stigma. The former pertains to the fear of being discriminated against while the latter to the actual cases of discrimination (Gabe et al. 2004). It is interesting to note that for Scambler’s (1989) respondents in his study on epilepsy, it was the fear of discrimination, which was most disruptive of their lives, rather than actual cases of enacted stigma. Stigma may be ‘enacted’ or ‘felt’ or both. Whereas, enacted stigma denotes discrimination by others, felt stigma represents (1) an internalised sense of shame and blame, respectively, and (2) a frequently disruptive and sometimes disabling fear of being discriminated against. The negative effects of felt stigma on the lives of people diagnosed or labelled with chronic or disabling conditions, including those with HIV/AIDS, has been well researched (Weiss & Ramakrishna 2001, Parker & Aggleton 2003, Scambler 2006, Scambler & Paoli 2008).

Discrimination arising from HIV-related stigma is a response to the fears and prejudices of individuals and communities (HRSA 2003). Manifestations of stigma vary according to time and place and are socially constructed (Scambler & Paoli 2008) but typically, they follow core social structures or ‘fault lines of society’ (Deacon & Stephney 2007, Walker 2007). This is exacerbated by fear, ignorance, anxiety, lack of knowledge, denial, shame, taboo, racism, xenophobia, moral judgements and by misleading metaphors like death, punishment, crime, war, horror and otherness (Ernesto et al. 2006).

Much of the literature on stigma is on the ‘micro’ or individual level. However, there is a need to move beyond such analyses to more ‘macro’ analyses. Parker & Aggleton (2003) reject the individualism underlying conventional approaches to stigma and its alleviation. Instead they insist that ‘stigma and stigmatisation function quite literally, at the point of intersection between culture, power and difference – and it is only by exploring these different categories that it becomes possible to understand stigma and stigmatisation not merely as an isolated phenomenon, or expression of individual attitudes or of cultural values, but as central to the constitution of the prevailing social order’ (p. 6).

Most of the research on HIV/AIDS-related stigma has been carried out in the United States and Europe where the spotlight has been on gay men, African-Americans and immigrants as carriers of HIV/AIDS (Deacon 2005). Although considerable research attention is now being directed towards Africa, Eastern Europe and Asia, further scientific research on HIV/AIDS-related stigma in sub-Saharan Africa is required, particularly in respect of the care and support of PLWHA (Parker & Aggleton 2003).
In the southern African context, it is important to understand HIV/AIDS-related stigma in relation to the broader social, political, economic and cultural environment, and to address stigma as one of a number of causes of discrimination and inequality, reluctance to test and to undertake treatment (Skhosana et al. 2006, Naidoo et al. 2007).

This paper is part of a larger study that seeks to understand the social and cultural complexity related to the provision and outcomes of ART in South Africa. It explores and analyses how patients on ART perceived and experienced stigma and how it has shaped their behaviour and their understanding of the disease.

**Methodology**

The study took place in a public-sector HIV/AIDS clinic in Johannesburg, South Africa. Although administratively, this clinic is part of a Community Health Centre it is physically separated from the rest of the centre. It is located some distance away in a renovated section of an otherwise unused hospital. The clinic started a rollout of ART in October 2004 following a long and protracted struggle for wide-scale provision of ART in the context of the government’s refusal to provide the necessary treatment (Nattrass 2007).

This is a qualitative study based on data collected by means of in-depth face-to-face interviews with a randomly selected sample of 44 patients who attended the HIV/AIDS clinic.

The field work took place between June and November 2007. Because of the technical difficulties in obtaining an accurate list of patients on ART, they were chosen on the day of the interview when sitting in the clinic’s waiting room. The choice was made randomly counting all patients at the time. Patients were approached for interview by two interviewers who could communicate in an indigenous language if needed. The interviews were conducted by research assistants who were specifically trained by the principal investigator. Once the chosen patients confirmed their availability, the aim of the study and purpose of the interview were clearly explained and written or verbal consent obtained.

As the lack of uptake of treatment by men is a well-recognised problem in South Africa we purposefully sought additional men for the interviews, but only succeeded in recruiting 12 men.

The interviews were conducted in one of the consulting rooms in the clinic, creating a private space to facilitate an open and confidential encounter. They lasted approximately an hour. The interviews were semi-structured, using an interview schedule as a guide only with the view of getting a ‘rich’ and detailed account of the subjects’ understandings, feelings and experiences (Yates 2004). Although, the interview focussed on the patients’ illness journey and experience with testing, diagnosis, help-seeking and treatment, the interviewers were trained to probe beyond that and encourage patients to talk openly about their lives with HIV/AIDS. The interviews were later transcribed and their content coded and analysed to identify core themes (Coffey & Atkinson 1996, Mason 1996). The two researchers independently identified core themes. The approach to the data analysis was based in the grounded theory approach where we sought to locate our conceptualisation and theorisation in the interview data rather than preexisting hypotheses (Strauss 1987, Yates 2004).

Ethics approval for the study was obtained from the Human Research Ethics Committee (Medical), University of the Witwatersrand, Protocol Number M070537.

**Findings**

Patients ranged in age from 16–59, the majority (32) being women. Respondents’ educational level varied from low primary school grades to post-matric diplomas. This was reflected in their various occupations such as domestic workers, sales consultants, construction and security employees; 50% of respondents were unemployed and 20% worked part-time. Most patients came from areas outside the clinic and faraway from Johannesburg. It is of importance to note that most had access to ART in the areas they came from, but chose to come to this clinic to maintain anonymity.

The findings from this study suggest that the fear of stigma plays a significant role in patients’ experiences of the disease from the early stages of testing and disclosure, to the initiation of, and commitment to, ART. It also impacts on their relationships with their families and on their intimate sexual experiences. The following sections of the paper outline these findings in more detail.

**Disclosure**

Public health policy outlines the benefits of public disclosure for HIV-positive persons and advocates campaigns for ‘coming out in public’ (Shisana et al. 2005). This, it is argued, will promote a climate of acceptance and therefore reduce the experience of felt and enacted stigma. However, the decision to disclose is a difficult and complex process, accompanied by risks associated with stigma. PLWHA are confronted by many factors that discourage disclosure such as: moral judgement and blame; ostracism by household or community; relationship termination; verbal and/or physical abuse as well as discrimination.
The interviewees in this study experienced and articulated many of these factors. However, fear of stigmatization and rejection is often the main factor behind lack of disclosure to family, employers and intimate/sexual partners, resulting in a ‘secret, shameful existence’ which, in turn, impacts negatively on the general attitude towards the disease and treatment commitments. The respondents in this study therefore relied very heavily on the clinic and the health workers from whom they received welcome support and understanding.

Respondents commented:
I did not tell my husband as he had previously revealed that he would kill me and the child if he knew we were HIV+. This made me feel bad and keep our status a secret.

I wanted to tell my family but couldn’t, I was afraid.

It was not easy to disclose my results to my employer, I was scared, I didn’t know my employer knew all these years...I was so scared to tell her.

My biggest fear was that people would reject me once they knew my status.

Popular perceptions of AIDS are shaped by a wide variety of factors including the contextual nature of HIV/AIDS-related stigma in different communities, people’s understanding of the source of illness and misfortune, the availability of life-prolonging ART and people’s exposure to ‘treatment literacy’ initiatives. The decision to disclose HIV status occurs within this framework (Almeleh 2006).

When I told my grandmother (about being HIV+), she got sick and died of shock and hurt from the news.

I wish this clinic was open on weekends since I have not had the courage to tell my employer I am HIV positive as I’m afraid this will result in me losing my job.

As the participants of this study come from many different communities, this diversity is reflected in the range of attitudes towards the virus, the disease and the treatment.

One respondent commented,
I had an aunt who died of HIV related complications; HIV is never discussed as a subject in my home. My mother thinks that HIV is like leprosy and those who have it are meant to be separated from the rest of society.

Another said,
My mother also has HIV, plus I used to have a rash that looks like a belt, in fact we call it a belt. The rash was very itchy and my mom would scratch it for me to relieve this itchiness, so that’s how I got infected with the virus.

Community perceptions of HIV/AIDS do not only reflect ‘innocent misunderstandings’ of the signs and symptoms of the disease. They may also be based on more malevolent attitudes and beliefs which are often directed towards women. Within this context people fear being identified as HIV positive, thus becoming the subject of wicked and malicious gossip by their communities. This is in-line with earlier research that highlights the role of witchcraft in fuelling the fear of being labelled HIV positive (Ashforth & Nattrass 2005, Almeleh 2006), and is consistent with our findings as well as many other studies in Africa.

For example two respondents commented,
I don’t want people to know. Not sure what they will say. I don’t trust my family in KwaZulu Natal, they talk a lot.

When I found out that I was HIV positive I thought of killing myself. I never told anyone as I did not want people to gossip about me, as it was evident in my neighbourhood that those that are HIV positive are spoken of as being promiscuous women who deserve to have this disease as it is a punishment for their sins. I did not want to be perceived as being promiscuous by others. The only people that can be trusted are the clinic staff members as they will not spread rumours about you and your status around like others.

Managing stigma entails working out strategies as a function of social circumstances and situations. A ‘felt stigma’ more often precedes an ‘enacted stigma’ rather than ensuing from it; and its consequences more seriously disrupt lives. This gives rise to strategies of ‘selective concealment’ in the workplace or in relations with others, as is the case in this study (Pierret 2003).

The strength of the fear of stigma is so immense that people are often willing to forgo the disability grant and other state support they are entitled to as indicated in the following case:

I’m trying to access the grant...I’m scared to fill in the forms, as they require my employer’s signature and this would make my status a public issue. It is my secret I do not need to reveal my status to anyone else.

Most of the respondents in this study were unable to access financial support from the state. While this indicates the limited support available and the difficulties in accessing it, it also underlines the extent to which the respondents, many of whom were unemployed, were prepared to go to keep their HIV-positive status a secret.

**Treatment**

As suggested thus far, disclosure or lack thereof is shaped by a web of factors linked to the fear of stigma.
Many of the participants waited some time before disclosing their status to family members, therefore delaying appropriate treatment, due to fears of others’ reactions. They also required time to come to terms with their diagnosis; to accept their status. One of the important contextual factors shaping HIV disclosure is the biophysical trajectory associated with HIV disease. The progression differs between individuals and is shaped by their socioeconomic and cultural context. With compromised immunity, individuals experience more and more opportunistic infections and are unable to conceal the symptoms of their condition. At this stage they also require greater care and support – the disease then becomes visible. Thus, as the biophysical trajectory plays out, the individual’s social relationships change (Almeleh 2006).

For many respondents in our study reluctance to disclose was rooted in fear of stigma. However, serious illness and the need for support due to health-concerns ‘forced’ some of them to disclose and seek treatment. The fear was surpassed by a need to engage with their significant others, particularly their immediate family, in order to deal with the physical manifestations of HIV-related illness, and receive emotional support and treatment. A commitment to treatment and the moment of disclosure coincided with the stage of initiation of treatment.

Respondents commented:

I could not manage any further. I felt very sick all of the time. I was tired and coughing and I was finding it very hard to work.

I think people could start to see, I was very ill. I could start to see. I could not avoid anymore.

One of the problems identified by this HIV/AIDS clinic (and many others) is the transient and diverse nature of the population on treatment. Many respondents did not use clinics in their local areas to avoid identification and stigmatisation among people who know them and their families. This is striking in the comment made by a young woman who highlights the magnitude of the fear of stigma and how it impacts on her treatment.

The community is not very supportive. They speak very negatively about HIV infected people hence I travel from Port Elizabeth to Johannesburg (1200 km) to receive my medication to spare my mother the shame in the community as she is a very well known person in the community.

Accessing treatment can therefore be circumscribed because of the fear of disclosure. However, serious illness and the more obvious physical symptoms of HIV/AIDS compelled respondents to seek help and disclose their status to selected family members, friends and employers.

Adherence

Although a full discussion of factors contributing to good adherence to ART is beyond the scope of this paper, it is important to mention in this context that overcoming the fear of stigma following disclosure has positive effects on adherence as illustrated by the following self-explanatory examples:

Support from Employers:

One respondent, a domestic worker, employed in a wealthy suburb in Johannesburg said:

I feel fine and manage to take my medication. I have a pills tray from my employer. The family I work for helps remind me.

Another respondent, similarly employed said:

My employer buys me veggies and encourages me and reminds me about my clinic visits. It has been important to have my employer. It has taken away the negative thinking and improved my health.

However, when the support is lacking, it presents a serious difficulty:

...sometimes I think about how my life is now dependent on tablets and hiding my medication to some people is a problem, especially at work.

I had an accident at work in 2003, I was nervous because my boss doesn’t know of my status. I was scared of loosing my job and how they will respond.

Support from partners:

An interviewee recalled:

I revealed my status to my partner; ...my partner helped me through this difficult time, we became highly dependent on each other as were both HIV+ and thanks to the medication [Prevention of Mother-to-Child Transmission Programme] the children are HIV negative.

These examples indicate that positively managing the effects of stigma have a beneficial impact on adherence to ART and ultimately to the management of the disease.

The role of family in stigma

In this research, families have played both a positive and a negative role in supporting family members who are HIV positive. This research indicates that families can isolate and embarrass and therefore compound stigmatisation yet they also work to support and help people through their diagnosis and on-going
treatment. Families can protect against the worst effects of stigma.

These respondents describe how they were let down by their families:

All my family know my status...families don’t treat you well. They won’t share spoons, bathroom...they watch you closely...nobody wants you to come when you are ill, especially my mother – they avoid you. They make harsh judgements about you, like when someone is naughty or bad, they say, ‘don’t be like this or else you will end up like Susan’ (name changed).

Families give you stress – if I knew, I would have kept quiet.

Families are the ones who are labelling.

I try to educate my family...but when you try talking about it you find they think/believe that you deserve it, that’s why you have the virus.

These comments are in sharp contrast to the experiences of men and women who received care and support from their immediate families:

My sister gives me all of the support I need, she is always a call away and she constantly wants to find out how I am. She is my support system and she has helped me along the road.

My girlfriend is the one person who constantly reminds me that I should be taking my medication, she has been my main anchor, even when I told her that I was HIV+ she did not leave me and with her family continuously stressing that she should leave me as she is HIV negative and she still stayed.

In some cases their positive response often surprised the patients themselves:

I was scared to tell my mother because she has heart problems...but my mother’s reaction was shock at first but supportive.

As with other diseases, these findings indicate that families play a significant role in the patients’ experiences. They have the potential to impact positively or negatively on the circumstances surrounding the patient and transform their social reality. However, in the case of HIV/AIDS in South Africa, families face acute dilemmas in the context of extreme stigma.

**Discussion and conclusion**

Almeleh (2006) argues that disclosure can have beneficial consequences including, reducing anxiety; increasing social support within the household and community; increasing access to treatment, care and support programmes; contributing to adherence benefits for those on ART; expanding awareness of risk to significant others; increasing opportunities for risk reduction within sexual relationships and enabling couples to make informed reproductive decisions.

However, the respondents in this study were reluctant to disclose their HIV-positive status because despite public assurances and encouragement, there is little guarantee of support and understanding. High profile HIV/AIDS education campaigns and individuals disclosing their HIV-positive status, it is hoped, would have had a positive effect, on the experience of being diagnosed with HIV/AIDS.

Yet, this study suggests that three decades into the epidemic, stigmatisation remains a core feature of the patient experience of HIV/AIDS. The wider provision of ART in health centre’s across South Africa has brought with it the expectation that people can be more accepting of HIV/AIDS and understand it as a chronic disease, which like many others, can be managed appropriately.

In the clinic in which this research was conducted, this was certainly the case, for patients and health professionals alike. HIV/AIDS was regarded as a chronic condition increasingly manageable by ongoing access to ART. However, this approach was not shared by many family members, neighbours and employers who held highly stigmatised views. Families are often condemned and stigmatised by virtue of their association with a family member who is HIV positive.

Posel (2004) argues that the stigma of AIDS, ‘leads families to banish children who are infected with AIDS; husbands chase away wives who have become sick with AIDS; everyday life is structured by strenuous regimes of public secrecy and disavowal of AIDS; priests are frightened to mention the subject of AIDS at funerals even when (and perhaps especially when) people know the cause of death’ (p. 23).

Drawing on Goffman’s (1963) notion of ‘courtesy stigma’ Walker (2007) argues, that family members, and partners of PLWHA, have been ‘stigmatised by association’. Walker (2007) describes households with sick family members who were not willing to identify themselves openly: ‘The community was not accepting that family anymore because they were always talking that she’s got AIDS and will pass it on to them and their children. The community hated them...’ (p. 86).

The more widespread provision of ART highlights significant contradictions and dilemmas regarding disclosure and treatment. Attending the HIV/AIDS clinic, adhering to a strict regimen of tablets, which inevitably interfere with work and home life, all draw attention to people who are HIV positive, sometimes making their HIV-positive status undeniable or certainly visible. Yet,
ART also holds the possibility of de-stigmatising the disease by virtue of transforming it into a life-limiting chronic disease, characterised by strict medical intervention and control, in much the same way that Parkinson’s disease, for example, and some forms of cancer are. Ashforth & Nattrass (2005) argue that stigma is related to the fact that having AIDS is ‘tantamount to saying a person is already dead’ (p. 292). They suggest that ‘Insofar, and for as long as treatment is successful the patient will seem healthy and the risk of pollution to others from contact with those ‘already dead’ will diminish along with the ‘stigma’ related to this’ (p. 292). Therefore, successful provision of ART can play a positive role in challenging many of the myths and fears which surround HIV/AIDS.

Despite surveys suggesting reduced levels of stigma (Shisana et al. 2005), the stigma surrounding HIV/AIDS in South Africa is debilitating and intrusive (Richter 2001, Simbayi et al. 2007). This pertains to covert stigma in particular. For example, in the Western Cape Province, HIV/AIDS is just called ‘ulwazi’, which means ‘that thing’. HIV/AIDS is seen, not only as a disease that has no cure, but as one which is so stigmatised, it cannot even be referred to by name (Morgan 2003).

According to Stein (2003), HIV/AIDS stigma is ‘the latest dirty secret’. General evidence points to a correlation between increased levels of HIV/AIDS knowledge and decreased levels of stigma (Parker et al. 2002). This suggests that HIV/AIDS stigma can be dealt with through appropriate education regarding the transmission of HIV/AIDS. However, this correlation could merely indicate that most people in South Africa, as elsewhere, are now aware that discrimination is ‘wrong’ and want to appear to researchers as more accepting of HIV-positive people than they actually are, thus validating the survey results. Research has shown that national health education campaigns, promoting the rights of PLWHA, as well as HIV prevention, have permeated most of South African society, particularly disclosure and treatment. Stigma permeates the experience of HIV-positive people on ART who participated in this study. While some respondents did report positive experiences and support from friends, family and employers in managing their illness, the intensity of HIV/AIDS-related stigma can threaten to compromise the value of ART, thus impacting on the daily lives of PLWHA.

Drawing on Castro & Farmer’s (2005) conceptualisation, we argue that access to ART ‘can spark a virtuous social cycle’ (normalisation), where patients confirm that their treatment alleviates noticeable signs of disease and facilitates their return to productive, ‘normal’ lives (p. 56). Successful access to ART can improve health to such an extent that PLWHA can for example, return to work, and, in the context of extreme poverty, provide for their families again. However, ‘perceived stigma’ remains a significant barrier that limits the potential full value of ART. Fear of the consequences of disclosure are greater than ‘feeling better’ due to ART. Therefore, while access to ART results in a return to the ‘virtuous social cycle’, for many, this opportunity is constrained by the power of ‘felt’ stigma. It is therefore the threat of stigma which restricts the value of treatment in this resource-limited setting.

**References**


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