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“I don’t want them to know”: how stigma creates dilemmas for engagement with Treat-all HIV care for people living with HIV in Eswatini

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“Treat-all” programmes aim to improve clinical outcomes and to reduce HIV transmission through regular HIV testing and immediate offer of antiretroviral therapy (ART) for those diagnosed HIV-positive, irrespective of immunological status and symptoms of disease. Global narratives on the benefits of Treat-all anticipate reduced HIV-related stigma and increased “normalisation” of HIV with Treat-all implementation, whereby HIV is remoulded as a manageable, chronic condition where stigmatising symptoms can be concealed. Drawing on Goffman’s stigma work, we aimed to investigate how stigma may influence the engagement of clinically asymptomatic people living with HIV (PLHIV) with Treat-all HIV care in Shiselweni, Eswatini (formerly Swaziland). This longitudinal research comprised 106 interviews conducted from August 2016 to September 2017, including repeated interviews with 30 PLHIV, and one-off interviews with 20 healthcare workers. Data were analysed thematically using NVivo 11, drawing upon principles of grounded theory to generate findings inductively from participants’ accounts.

Stigma was pervasive within the narratives of PLHIV, framing their engagement with treatment and care. Many asymptomatic PLHIV were motivated to initiate ART in order to maintain a “discreditable” status, by preventing the development of visible and exposing symptoms. However, engagement with treatment and care services could itself be exposing. PLHIV described the ways in which these “invisibilising” benefits and exposing risks of ART were continually assessed and navigated over time. Where the risk of exposure was deemed too great, this could lead to intermittent treatment-taking, and disengagement from care. Addressing HIV related stigma is crucial to the success of Treat-all, and should thus be a core component of HIV responses.

Keywords: adherence, asymptomatic, qualitative, retention, Swaziland, “Test and Start”

Introduction

“Treat-all” programmes are being implemented in several African settings, as a HIV prevention and treatment strategy. In line with recent World Health Organization (WHO) guidelines, regular HIV testing is encouraged and antiretroviral therapy (ART) is offered immediately for those who are diagnosed HIV-positive, irrespective of immunological status and symptoms of disease (WHO, 2015). Global narratives on the benefits of Treat-all implementation anticipate that earlier and increased access to ART will facilitate the “normalisation” of HIV, where it is considered a manageable chronic condition, and where stigma can be reduced through management of HIV related symptoms enabling HIV status concealment (Abadia-Barrero & Castro, 2006; Roura, Urassa, et al., 2009; Roura, Wringe, et al., 2009b). Castro and Farmer (2005, p. 57) describe this transformation of HIV from a fatal disease to a chronic, manageable one as having “decreased stigma dramatically in Haiti”.

Stigmatisation can be defined as a social process occurring in the context of power, where an individual’s difference, condition or attribute is considered unfavourable and linked to negative stereotypes (Link & Phelan, 2001, 2006). While the manifestations of stigma are socially constructed and context specific, possessing such an attribute generally results in loss of status, devaluation and discrimination, and leads to unequal outcomes for the stigmatised individual (Gilbert & Walker, 2010; Goffman, 1963; Link & Phelan, 2001; Parker & Aggleton, 2003; Steward et al., 2008). In his seminal work on stigma, Goffman (1963) outlined the distinction between “discredited” and “discreditable” identities. Those who are discredited possess an evident or visible attribute, requiring them to devise coping mechanisms to manage the resulting prejudice and discrimination, which can also be referred to as “enacted stigma”. Conversely, conditions which can be hidden from the public eye create discreditable identities, where the main focus is managing and concealing information to “pass” as “normal”, to avoid becoming discredited and experiencing

the expected resultant stigma, which can also be referred to as “anticipated stigma” (Goffman, 1963; Scambler, 2009; Steward et al., 2008).

A growing body of work has explored the relationship between stigma and taking ART. Mattes (2014) refers to ART as a “technology of invisibilisation”, as it provides an opportunity to maintain status secrecy and to thereby avoid stigma, a concept which is also reflected in the work of other scholars (Beckmann, 2013; Moyer, 2012). However, while ART may enable the avoidance of enacted stigma (Beckmann & Bujra, 2010) and prevent people living with HIV (PLHIV) from being discredited, anticipated stigma can persistently prevail in people’s lived experiences with HIV (Alonzo & Reynolds, 1995). PLHIV remain discreditable, partly due to the potential for symptom development and status exposure, but also because ART does not directly address the structural drivers of stigmatisation (Russell et al., 2016), such as poverty, gender inequality and racism (Link & Phelan, 2001). Stigma reflects the workings and forms of social inequality, and to properly understand it we must consider how some people come to be socially excluded, and the forces that create and reinforce such exclusion (Parker & Aggleton, 2003). Additionally, ART does not address the fundamental causes of stigma, including the deeply held views of powerful groups that lead to stereotyping and labelling (Link & Phelan, 2001), and Squire (2010, p. 409) argues that the association of HIV with “transgressive sexuality, particularly for women, will always render it socially pathological”.

HIV related stigma presents a major barrier to the prevention and treatment of HIV (Mbonye et al., 2013; Stangl, Lloyd, Brady, Holland, & Baral, 2013; Steward et al., 2008). In African settings, and particularly in Southern and Eastern Africa, stigma has been found to discourage care-seeking (Maeri et al., 2016), and undermine uptake of HIV testing, ART initiation and adherence (Bond, 2010; Genberg et al., 2009; Mbonu, van den Borne, & De Vries, 2009; Mbonye et al., 2013; McGrath et al., 2014; Orne-Gliemann et al., 2016; Sengupta, Banks, Jonas, Miles, & Smith, 2011). Stigma can undermine adherence and engagement directly, where attempts at status concealment such as hiding treatment or selecting clinics far from home contribute towards treatment interruptions (Dlamini et al., 2009; Gilbert & Walker, 2010; Katz et al., 2013). There are also indirect influences, whereby non-disclosure of HIV status results in lack of social support and treatment reminders (Katz et al., 2013). While this body of research explores stigma and HIV service engagement for symptomatic PLHIV, where the discrediting attributes are made visible by the disease itself, it is not yet known how this may be experienced by clinically asymptomatic PLHIV in the context of Treat-all, where the discrediting risk is made manifest only through accessing treatment.

Supporting PLHIV to engage with treatment and care is important for individuals’ health outcomes, as delayed treatment and suboptimal adherence have deleterious effects on morbidity and mortality (INSIGHT START Study Group, 2015; Song et al., 2018; TEMPRANO ANRS 12136 Study Group, 2015). Additionally, suboptimal adherence can contribute to drug resistance, which can be transmitted, with resultant population level and individual level risks, and

which has been highlighted as a critical threat to eliminating AIDS by 2030 (WHO, 2017a, b). Without detailed exploration of whether and how stigma is manifested and experienced in this context, it is unknown how it may undermine Treat-all efforts. To ensure stigma is addressed, it must first be understood, ideally by examining the perspective of those affected. In this context, we aim to examine how stigma shapes PLHIV experiences with HIV, and engaging with HIV treatment and care services under Treat-all in Shiselweni, Eswatini (formerly Swaziland).

Methods

This study is situated within the context of a broader research project that used a longitudinal qualitative design to examine the lived experiences of clinically asymptomatic PLHIV, their engagement with HIV treatment and care, and how these changed over time in the context of Treat-all in Shiselweni, Eswatini.

The study of lived experiences refers to understanding individuals’ experiences, choices, and options, and how individuals interpret and make sense of their experiences (Given, 2008; Smith, 2004). This approach aims to understand and describe individuals’ experiences of their everyday world as they see it (Liamputtong, 2013), and to remain as faithful as possible to the phenomenon and the context in which it appears in the world (Giorgi & Giorgi, 2008).

Study context

Eswatini has the highest reported HIV prevalence worldwide, estimated at 35% among women and 19% among men aged 15–49 years (UNAIDS, 2016). HIV prevalence peaks at 54% among women aged 35 to 39 years and 49% among men aged 45 to 49 years (Swaziland Ministry of Health, 2017). Most transmission occurs through heterosexual sex (Swaziland Ministry of Health, 2012).

Eswatini is the last remaining absolute monarchy in Africa. Classified as a lower middle-income country, it is a small, largely mountainous country with a population of 1.2 million people. Sixty per cent of the population lives in poverty, of which 38% live in extreme poverty, and income inequality is high (World Bank, 2018). Limited economic opportunity and high unemployment have resulted in widespread dependence on labour migration, with most migrant labourers travelling to neighbouring South Africa for work (Hickel, 2012). Most people identify as Christian (90%), and the main land use is pastoral, and timber forest (CIA, 2018). In the predominantly rural southern region of Shiselweni subsistence farming is widely practised, and the region has been particularly affected by drought in recent years, which has caused food insecurity (Root, Van Wyngaard, & Whiteside, 2017).

In October 2014, a Ministry of Health/Médecins Sans Frontières (MoH/MSF) Treat-all implementation pilot began in the predominantly rural Nhlngano health cluster in the Shiselweni region. This aimed to contribute towards reduced HIV incidence and improved clinical outcomes for PLHIV. The population in Nhlngano largely access HIV treatment and care at primary health clinics. The area has eight primary clinics and one secondary health facility; some people have to travel long distances, often on foot, to

reach the nearest clinic. Treat-all was rolled out nationally in October 2016.

Participant recruitment

Participants were recruited purposively to include PLHIV enrolled in the Treat-all pilot programme who were considered clinically asymptomatic and who would have been otherwise ineligible for treatment at the time of ART offer (CD4 count ≥ 500 , WHO disease stage 1), and to include a range of treatment-taking experiences (see Table 1). The project patient cohort was stratified for gender and age, to include young people (aged 16 to 25 years) and adults (aged 26 to 49 years). Healthcare workers (HCWs) from the facilities implementing Treat-all (one secondary and eight primary care facilities, not HIV-specific) were purposively recruited to include a range of positions involved in the delivery of HIV testing, treatment and care, and both

MoH and MSF personnel. Fieldwork was conducted from February 2015 to November 2017. Identified PLHIV were contacted in June 2016 and invited to participate in between 2 and 4 interviews over a 12-month period, while healthcare workers (HCW) were invited to participate in 1 interview during March and April 2017.

Attempts were made to contact 107 PLHIV identified for potential recruitment, 55% of whom ($n = 59$) were non-contactable. Of those who were contactable ($n = 48$), 30 agreed and participated, 9 agreed and did not attend the agreed appointment (reason for non-participation unknown), 2 refused due to work commitments limiting their time in the area, 5 were out of the region and 2 were unwell and therefore unable to meet. All HCW who were approached and invited to participate agreed to an interview.

Data generation and analysis

In-depth interviews were conducted to explore a range of topics relating to PLHIV's lives, their experiences of living with HIV, and with treatment and care (see Table 2 for a summary of topics). Interviews were based on topic guides but were primarily participant-led, for example, HIV status was not asked about unless participants themselves disclosed their diagnosis (which all participants did). Multiple waves of data generation were conducted to capture changes over time, and also to benefit from developing rapport between participants and the researcher, which produced richer quality data. Data generation and analysis followed an iterative process, with topic guides for subsequent interviews being based on initial findings, to further test and explore particular areas emerging as potentially important. Interviews were conducted in siSwati by same-gendered interviewers, mostly held at participants' homes, or another location of their preference if they felt more comfortable (e.g., fixed testing site in town). The interviews were audio-recorded following participant consent and were then translated and transcribed. Interviews with HCW were conducted at clinics, mostly in English, and explored topics relating to their experiences implementing Treat-all including offering ART to those considered clinically asymptomatic, supporting patients, and related challenges faced by patients and HCW.

Interview transcripts were analysed thematically using NVivo 11, drawing on principles of grounded theory to generate findings inductively from participant accounts and to actively investigate discrepancies from the majority of themes (Bradley, Curry, & Devers, 2007; Glaser, 1999; Glaser & Strauss, 1967). Initial coding and themes were discussed collaboratively, with a coding framework developing as analysis progressed. Repeated

Table 1: Participant characteristics

Participant information*	<i>n</i>
All PLHIV	30
Treatment-taking category	
On ART	18
Lost from treatment	12
Enrolment period	
Early (October 2014–March 2015)	13
Mid (April 2015–September 2015)	12
Late (October 2015–March 2016)	5
Gender and age	
Women	18
Young women (17–25 years; average 21)	9
Adults (26–46 years; average 33)	9
Men	12
Young men (16–25 years)	0 (none eligible in patient cohort**)
Adults (26–49; average 37 years)	12
All HCW	20
Position	
Nurse supervisor	5
Nurse	8
Adherence counsellor	5
Doctor	1
Employer	
MoH	12
MSF	8

*Participant information relates to that recorded on the project patient database at time of recruitment, or for HCW the positions they identified with during interviews

**No young men were eligible due to the epidemiology of HIV in Swaziland meaning fewer young men are infected, and additionally men can access care later.

Table 2: Longitudinal interview time frame

Interview	Date range	Participants (<i>n</i>)	Meetings (<i>n</i>)
1. Life history, family and relationships, hopes and aspirations, key life events	22/08/16–31/10/16	30*	33
2. HIV testing, diagnosis, treatment offer and treatment initiation decision-making	17/11/16–07/02/17	29	31
3. Living with HIV, ongoing treatment-taking and engagement with HIV services	25/03/17–08/09/17	26	27

*Certain interviews were conducted over more than one meeting, for example, due to length of discussion and available time; one participant was lost to follow-up after the first interview, attempts were made to contact her but she was not available to arrange another meeting; three participants completed two interviews and one completed four interviews.

interviews with PLHIV were initially analysed per round to examine themes across participants' accounts, and then longitudinally to explore how patients' narratives changed over time. Ethical approval was received from the Swaziland Scientific and Ethics Committee, London School of Hygiene and Tropical Medicine and from MSF Ethics Review Board. Pseudonyms are used in this paper for PLHIV participants, and HCW participants are referred to as HCW, to ensure confidentiality.

Results

In total, 106 interviews were conducted between August 2016 and September 2017, including 86 interviews with 30 PLHIV (Tables 1 and 2) and 20 interviews with HCW (Table 1). Stigma emerged inductively from participants' accounts of living with HIV and engaging with HIV treatment and care services. Stigma was then explored further in later interviews to gain greater depth of understanding into the ways in which it affected individuals' sense of identity, their interpretation of their diagnosis, and their engagement with treatment and care. HCW interviews also highlighted the ways in which stigma frames and influences PLHIV's engagement with treatment and care in the context of Treat-all. Figure 1 shows a summarised depiction of these findings.

HIV status concealment to avoid anticipated stigma

Anticipated stigma was pervasive within PLHIV participant narratives, and almost all described feeling that they must conceal their HIV status to avoid stigma through being singled out and treated differently by those around them. The importance of status secrecy also appeared reinforced through health messaging at the point of treatment initiation and subsequent clinic visits, with some health workers encouraging their patients not to widely disclose their diagnosis.

When you are HIV-positive you must keep it a secret (Hlobisile, woman (F), second interview).

They [HCW] said going around telling people isn't a good thing... they explained this to us at the clinic that we should tell someone who will not go around talking about you (Cebisile, F, third interview).

Many PLHIV feared the potential negative consequences of having their status discovered. The fears should they be identified as taking treatment included not wanting to be gossiped about, made a mockery of, or to experience social judgement which could result in loss of reputation, social stature and standing, which in turn could impede future relationship and marriage prospects.

It lowers your value when people point at you for taking the treatment. People will not respect me the way they do now, and they will not treat me the way they treat me now (Nokuthula, F, second interview).

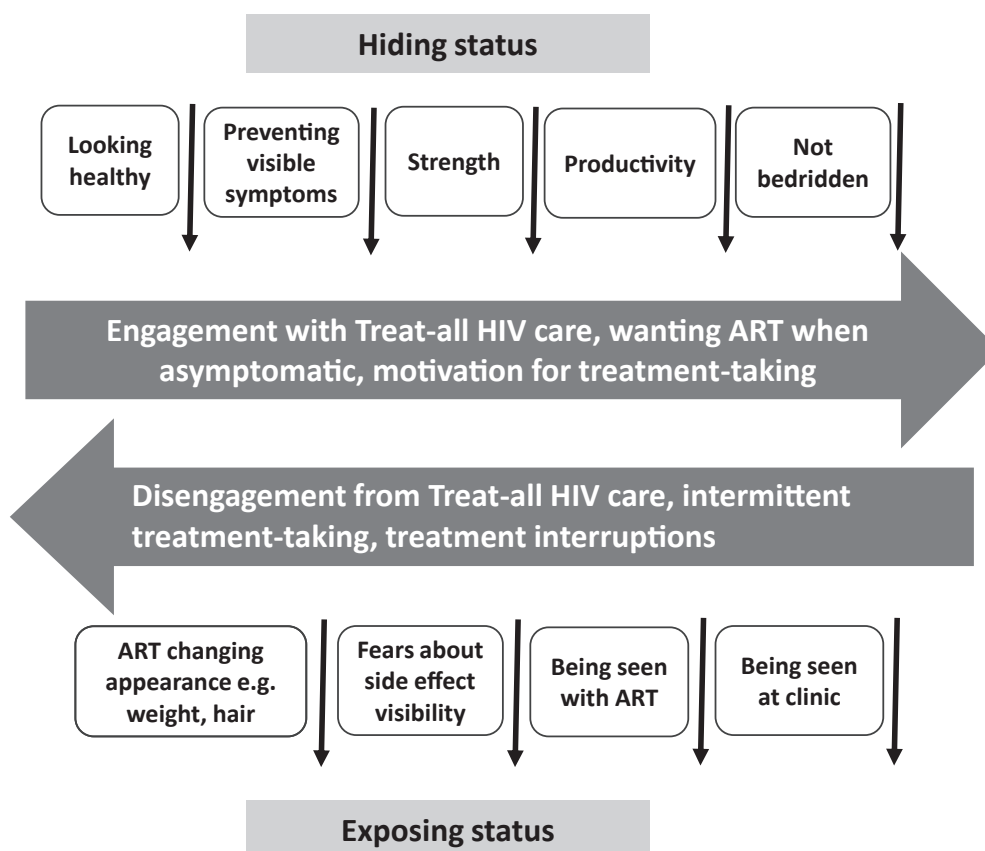


Figure 1: How stigma and status concealment versus exposure influence PLHIV's engagement with HIV treatment and care under Treat-all

Commonly held notions of what comprises a good, outstanding citizen, in line with Christian values and moral standards, appeared contradictory to, and threatened by, views about who gets HIV. Most participant accounts included references to the ways in which HIV continues to be abnormal and morally judged, particularly linked to the sexual nature of transmission, and with negative connotations regarding the sexuality and behaviour of PLHIV.

I wish that people could take AIDS as a common cold, because it can get anyone, not that they take you as an animal, or that you were living a life that is not good, you see (Thandi, F, first interview).

Religion comes in, and if you do go to church we don't expect you to be having sex when you are not married, but you are actually having sex, so you can't talk about it (laughs) and then at the same time this is a very small community, so everybody knows everybody. I know you go to church, and if I then know that you are sleeping with this one, it means you are not actually an outstanding Christian if I may say (HCW).

The impact of such anticipated stigma could be strong and harmful. Some participants described considering suicide, linked to the humiliation, shame and devaluation that could come from having their status known:

I even wished to kill myself because I had lost so much weight and people in the community were making a mockery of me (Sanele, young woman (YF), second interview).

ART offering the potential to maintain good health and a hidden HIV status

Initiating ART while still largely asymptomatic and with good general health, offered both risks and opportunity. ART was a means to avoid signs or symptoms of ill health from developing, which could expose one's HIV status. Avoiding HIV visibility appeared more important than maintaining good health itself, with the fear of being identified being more pervasive than the fear of experiencing sickness.

I should just start taking the treatment while I am still walking on my own, while I am still healthy, and I shouldn't go down but instead I should improve from where I am now... so that I wouldn't lie down and be identifiable and then lose weight and many other things (Vusi, man (M), second interview).

Maintaining good health, including strength and energy, enabled the maintenance of a sense of normality, being able to work and function as a member of society, contradicting stigmatising processes of "othering" and countering feelings of no longer being a human. This appeared particularly important for men, who described wanting to work and provide for their family, thereby upholding notions of masculinity and productivity.

When I'm healthy, my family will have something to eat and my children will be able to go to school and they wouldn't have problems... if I might get sick then I think my children will struggle because what they get from me it's something they cannot get from anyone [else] (Mandla, M, second interview).

Many participants described having seen the effects of delayed ART initiation, for example, with family members or

neighbours becoming sick and bedridden, which reinforced their motivation to start treatment before succumbing to these symptoms:

I saw from my sister, she started them late when she was very sick and I said I do not want to get to that stage, let me start them while I am walking because when you are sick people then start to gossip about you (Sanele, YF, third interview).

Though all participants were considered clinically asymptomatic, several described experiencing embodied signs of HIV, such as headaches, weakness, lethargy and weight loss, which served to warn them of the potential for imminent health deterioration and therefore HIV visibility without ART. Perceptions of health and ill-health appeared to differ experientially from biomedical definitions regarding the severity of HIV related disease (e.g., those included in WHO disease staging). For some, even receiving a HIV diagnosis pointed to a fragility in their health status, reinforcing their sense of needing to start ART.

When you haven't tested, you are going to tell yourself that you're okay but once you have things like constant headache and things like that, you must know that those are the signs... We know the symptoms, like if your hair is like it has been licked by a calf... Forget it just go and start taking the treatment, there's nothing you can do (Jabulane, M, second interview).

It hurt me... [after HIV diagnosis] you then begin to see yourself that you're not someone who is healthy, you're someone who is sick (Sifiso, M, third interview).

Health workers also felt that a key driver for PLHIV to initiate ART before becoming symptomatic was the ability of ART to hide their status, relating this to anticipated stigma.

Usually it is that they don't want to be sick, to be seen by everyone that this one is now sick... once you get sick, be in a wheelchair, they [community members] diagnose you as being HIV positive... there will be rumours all over. They still want their status to be confidential. They test and initiate but are not ready to disclose in public. It is self-discrimination (HCW).

[Treat-all] has helped us greatly because if a person is initiated today on ART nobody will see that the person is HIV positive because there are no hair changes and no nothing. By that the stigma... because once the symptoms... manifest, discrimination begins... (HCW).

In addition, certain HCW alluded to this message being reinforced in pre-ART sessions with PLHIV:

They eventually want to take them because we tell them: why do you want people to see you that you are sick? Because you could take even when no one is noticing, and you will continue (HCW).

As well as wanting to initiate ART to ensure HIV status concealment, the perceived need for, and benefit of ART in enabling a hidden status was said to motivate ongoing, continued treatment-taking:

The thought of stopping treatment never crossed my mind because I am the one who will get exposed if I stop taking them... I respect them [ARVs] a lot they

have helped me, if it was not for them, I would also be visible that I am sick, so really I respect them a lot (Welile, F, third interview).

The risk of HIV status exposure undermining engagement with HIV treatment and care

While many PLHIV appeared motivated to take treatment early to protect a hidden status, engagement with HIV treatment and care services could itself be exposing and therefore discrediting. Almost all participants described fears of being seen at clinics, or having their treatment found:

When you are going to the hospital you are ashamed, even just walking around you are ashamed because you know that people know that you are positive, and then others will point you using their heads and have names for you, you find that they call you Khumalo [one who takes] (Sanale, YF, third interview).

Many PLHIV could go to great lengths to hide their treatment, and at times these efforts undermined their capacity to take it. For example, a dose may be missed when others were present to avoid being seen and therefore exposed:

Sometimes you would find that when the time for taking the treatment comes he is also in the room, so it would happen that I wouldn't take them (Nelisiwe, YF, third interview).

I am scared to say 'yey people get out so that I can take my bag and drink my treatment'. I am scared, so I end up skipping, and this makes me stressed (Nontokeko, YF, third interview).

Participants also reported that they feared the risks of being seen at the clinic while queuing for ART refills. Some described strategies they adopted in order to minimise this risk, including befriending HCW to avoid the need to queue, or choosing a clinic further from their home community to avoid the risk of being seen by neighbours. However, these strategies were often fragile or less convenient, which inadvertently added to the burden and fragility of treatment-taking. This could potentially undermine the sustainability of longer-term engagement with treatment and care. The strategy of selecting a clinic which was further away from home in order to avoid exposure was particularly described by young women and by men, who were less easily able to justify their presence at the clinic by citing an alternative and more socially acceptable reason than, for example, older women.

I do not want to lie to you [interviewer surname], I have never queued and I feel like I am scared to. I feel like I am not ready to be seen by everyone that I am HIV positive. You see where you sit there, I have never sat there... I just come and go inside (Hlobsile, F, third interview).

I transferred from Nhlango to Big Bend... aunt said I should transfer because people around here know me, so they might know me and see me and be gossiping about me... she said it is better that I go where they do not know me (Thobile, F, second interview).

Some PLHIV also described times when they turned back from the clinic without collecting their refill due to seeing

someone they knew at the clinic and not wanting to be exposed:

They said because I am pregnant I have to go to the VCT and when I looked at it the Nhlango VCT the way it is, I just left everything there and then... it exposes too much sisi... I was like I will be discovered by people I work with... so I was like no ways (Welile, F, second interview).

Someone might decide to leave the treatment because there's a relative of mine in the clinic, or the cleaners or something, she knows me and she's going to talk (HCW).

Although early initiation on to ART was understood to prevent symptom development, some saw ART itself as concomitantly potentially exposing, with fears that treatment side effects could cause physical deformities, changes in weight, hair and skin colour. This is indicative of the dilemma that the prospect of Treat-all posed for asymptomatic PLHIV, as ART could be the catalyst for their status to become noticeable, with treatment related side effects perceived as potentially revealing their HIV to others.

I do not want to lie, part of me was saying I should take them but another part was saying I shouldn't take them... I am scared of them making a problem of me and I would be like a written book, look at her she doesn't have a big belly anymore, she is finished with a flat ass, you are now written that you are taking treatment you see, I was scared of them, telling myself that they [ART] will expose me (Hlobsile, F, third interview).

I thought that the treatment would make me sick and I would be seen by all people because I would've changed so much than what I was before (Lindiwe, F, second interview).

I was actually afraid of gaining weight because it was now a common thing that once you gain weight, whether I have told this person or not, but once I gain weight they are going to say I have started taking the treatment... I was really afraid that people were now going to identify me easily (Mandla, M, third interview).

Maintaining a hidden HIV status whilst engaging with HIV treatment and care services thus appeared fragile. Participant accounts were interwoven with calculations of perceived benefits and risks of treatment-taking and status exposure, which were continually considered and navigated over time. If the risk of exposure was deemed too great, this could cause individuals to disengage from treatment and care services:

It is not pleasing to be on a treatment for the rest of your life, and also that you can hide it today but for how long? Because there are people that you do not want to know about you taking treatment... you can hide it from them today and tomorrow, but they will end up finding out about it because the hospital is not mine alone (Nontokeko, YF, third interview).

When you are talked about, and when you are scared, you may end up saying let me just stop taking this thing. This is what can make people stop taking treatment (Sanele, YF, third interview).

I was not collecting them anymore... what was in my mind was that I was scared to tell my boyfriend that it is my time to collect my treatment, I was scared to do that... (Ncobile, YF, fourth interview).

HIV status acceptance countering anticipated stigma

The extent to which PLHIV's engagement with HIV treatment and care services was framed by avoiding exposure and anticipated stigma appeared to be influenced by their own interpretation of their diagnosis. Only four participants did not mention trying to hide their status, and for these participants, their own acceptance of being HIV-positive and wanting to live seemed to support their overcoming fear of others' judgement, thereby also supporting their engagement with care.

Whatever situation you go through, what will help is that you accept yourself first, so that you get accepted by other people. When you start having self-stigma [utinyandza wena], then at that time you feel like I am not the same as other people... I accepted myself a long time ago, in the beginning. That is what made me live, that I just accepted myself. I never found myself as different, even if you could come and say "I am not positive", that does not hurt me... I find that we are the same. You can be negative and I know that I am positive, it does not make any difference to me... when they said I am positive so what, there is treatment, they say it helps, I will continue to live (Philile, F, second interview).

Such acceptance of status could be challenging in the absence of any symptoms or signs of ill health. Some did not perceive the need for ART in the absence of symptoms, questioning their diagnosis or the likelihood of experiencing future health deterioration, and wanting to wait before starting ART:

I thought for myself that I do not have to take them because I feel okay... maybe when I get sick and I can see that I have to take the treatment (Gcinile, F, second interview).

Some... they say they are not ready, they are still fine... they tell you that there is no need, they will start treatment when they are sick, not now (HCW).

Treat-all could expedite the time from HIV diagnosis to treatment initiation, but for many it appeared important to have time to process and come to terms with a HIV diagnosis, to feel ready for treatment, and for people to know.

I think it is still processing for me to accept it... I think that after some time I will end up not caring if people know, it is just for now... (Nokuthula, F, third interview).

I think that as time goes on I will be alright, I will then accept it... but I do not know yhihi... what can be done... it is still new, just like losing a mother, you keep thinking about her but as the years go by you then forget that she died and I cried at the funeral. So I think I will also be alright (Nontokeko, F, third interview).

Discussion

In the context of Treat-all, in a setting with a high prevalence generalised HIV epidemic, stigma was pervasive and influential in participants' accounts of living with HIV, and appeared to strongly frame PLHIV's engagement with treatment and care services. On the one hand, treatment appeared as a pulling force, offering the potential to preserve good health, so that any symptoms which may expose HIV could be avoided. This motivated many PLHIV to want to start treatment early, when considered clinically asymptomatic. However, being on treatment and engaged with HIV care services could also be exposing, and many had fears around being seen collecting refills or having their treatment discovered, which could undermine their engagement. Avoiding anticipated stigma appeared so important that some participants thought of suicide if they were to be discovered living with the virus, and to experience the expected humiliation and devaluation that could result. While there is a wealth of research on HIV related stigma and its interplay with use of HIV services, to the best of our knowledge this is the first study to unpack in detail the ways in which stigma influences asymptomatic PLHIV's engagement with Treat-all.

Status concealment appeared as an information management strategy, through which PLHIV maintain a discreditable identity and avoid becoming discredited (Goffman, 1963). The need to conceal was reinforced by health messaging at clinics, potentially implying that there is something inherently wrong with being HIV-positive (Bernays, Papparini, Seeley, & Rhodes, 2017). Our finding that almost all participants felt they must conceal their HIV status due to anticipated stigma has been shown by others (Alonzo & Reynolds, 1995; Dlamini et al., 2009; Katz et al., 2013). While all PLHIV participants were considered clinically asymptomatic, several described embodied signs of HIV, which served to warn them of the potential for imminent health deterioration and discrediting without ART, and supported their motivations for initiating ART. This also highlights the dissonance between biomedically ascribed markers of HIV (e.g., CD4 count and WHO disease stage) and PLHIV's experiential conceptions of their health and illness.

The ability of ART to alleviate physical manifestations of HIV have led to it being referred to as a technology of "invisibilisation" (Beckmann, 2013; Mattes, 2014), enabling social and economic engagement, and therefore providing PLHIV with a sense of value (Bernays, Rhodes, & Terzic, 2010; Campbell et al., 2011; Mattes, 2014). In our study, this manifested in the ability of ART to prevent the development of physical symptoms, rather than alleviate them once present. Other studies describe the transformative and restorative effects of ART when taken by PLHIV who are very unwell, which can then motivate adherence (Bernays, Seeley, Rhodes, & Mupambireyi, 2015; Russell & Seeley, 2010). Our findings that participants were motivated to start and continue taking treatment in the absence of symptoms show how the relationship with ART, and its capacity to conceal HIV, are changing under Treat-all.

While ART can present a technology of "invisibilisation", some authors have suggested that wider treatment availability can generate new forms of stigma (Roura, Urassa,

et al., 2009). Although being visibly healthy can conceal an HIV-positive status, clinic visits and daily medication use can create privacy concerns and risks of exposure (McGrath et al., 2014; Moyer & Hardon, 2014). Many PLHIV in our study had concerns about the risk of exposure from engaging with treatment and care, which could cause intermittent treatment-taking, interruptions and disengagement from treatment and care. Hiding treatment can lead to non-adherence and treatment interruptions (Dlamini et al., 2009; Katz et al., 2013; Maeri et al., 2016), and in our study several participants described times when they felt unable to take their medication if others were present.

The extensive efforts PLHIV in our study described in order to maintain privacy, such as choosing to attend clinics long distances from their home communities, have been found by others (Bond, 2010; Gilbert & Walker, 2010; Maeri et al., 2016), and as affecting individuals' ability to remain adherent to ART (McGrath et al., 2014), for example, through increasing the burden of treatment and undermining longer-term sustainability. However, our findings illustrate the dilemma that individuals experience because some perceive that not engaging in treatment, in the hope of continuing to remain asymptomatic, may allow a continued invisibility of their HIV status for longer. In the past, the risk of exposure from engaging with treatment could potentially be balanced with the risk of exposure from visible signs of HIV before starting ART. In the Treat-all context, where PLHIV were visibly asymptomatic before initiation, these risks of exposure may actually seem greater with treatment-taking than without it, as the risk of developing symptoms in the future are perhaps more abstract and less current than those experienced presently. There is a risk that the effect of this is to delay treatment-seeking. Likewise, while some studies have found that PLHIV may have concerns about visibility linked to ART side effects (Mattes, 2014; Mbonye et al., 2013, 2016; Zhou, 2016), in our study these concerns could influence the cost-benefit weight of ART unfavourably, as treatment may be felt to cause changes to appearance which were more exposing than PLHIV's health before starting. If these perceived risks are not addressed within programmes, this could undermine the success of Treat-all implementation.

Self-acceptance of HIV status appeared to counter stigma, helping individuals to overcome the fear of others' judgement and not to internalise stigmatising attitudes and shame. The influence of HIV status acceptance on PLHIV's engagement with treatment and care in Swaziland is reported elsewhere (Horter et al., 2017). Others have found that status acceptance has supported the choice to live, to overcome fear of stigma and to support adherence (Gilbert & Walker, 2010; Katz et al., 2013; Nixon et al., 2018). We found that some PLHIV felt it could take time to process and come to terms with an HIV-positive result, which may be expedited under Treat-all as the time between diagnosis and treatment initiation can be reduced. This highlights the importance of considering individual patient readiness and acceptance of HIV status within Treat-all and same-day treatment approaches.

Many authors have described the ways in which HIV is associated with immorality and deviant sexual behaviour

(Mattes, 2014; Mbonu et al., 2009; Mbonye et al., 2013; Moyer & Hardon, 2014; Roura, Wringe, et al., 2009; Roura, Urassa, et al., 2009), with PLHIV therefore being blamed for their infection, and HIV deemed as a punishment for those who have challenged sexual and gendered social norms (Campbell et al., 2011). HIV stigma can thus be seen as central to the establishment and maintenance of social order (Foucault, 1977, 1978; Parker & Aggleton, 2003) and control of sexual behaviour (Mbonu et al., 2009), which can be reinforced and upheld by religion, with PLHIV being considered sinful or evil (Alonzo & Reynolds, 1995; Duffy, 2005). This is of particular relevance in the study setting, where the population is predominantly Christian, and participation in religious and church activities are an important part of culture and personhood.

Several studies have shown that individuals judged in association with HIV and immorality can experience great shame, indignity and humiliation (Campbell et al., 2011; Gilbert & Walker, 2010; Mbonu et al., 2009; Mbonye et al., 2013). Respectability is an important aspect in the social construction of value and personhood (Campbell et al., 2011), lending understanding as to why several participants in our study who anticipated stigma also contemplated suicide. Our finding mirrors that of Moshabela et al. (2016, p. 27) in South Africa, where it was felt "better to die with dignity, than live with shame" from being known to be HIV-positive. Additionally, a study conducted in the same region of Swaziland as our study (Shiselweni) reported suicidal ideation following HIV diagnosis and as a result of anticipated stigma (Root et al., 2017). However, there is also a powerful strand of "responsibilisation" which could be emphasised, where initiating ART early allows for continued productivity. This could be particularly effective for men, by appealing to the prevailing discourse of masculinity, which is imbued with the need to provide for their families (Siu, Seeley, & Wight, 2013). These findings highlight the importance of understanding and considering the social experiences of individuals as integral to the HIV response, and the need to acknowledge stigma and its influence on PLHIV's lived experiences.

The longitudinal approach that was adopted in our study supported rapport and relationship building between interviewer and participant. This helped with the discussion of sensitive topics such as stigma, and facilitated access to alternative layers of participants' narratives, beyond those deemed to be socially acceptable. This approach also enabled a greater depth of understanding, and insight to the nuanced ways in which stigma accounts changed over time. These findings are situated within a specific time and place, relating to a fairly early stage in the Treat-all pilot, where it was uncommon for people who were relatively healthy to be accessing ART, and before national implementation. It will therefore be important to see how these findings continue to evolve as Treat-all becomes more commonplace. While likely to be of relevance to similar contexts, our findings reflect the voices of particular participants in a particular context, and therefore should be considered with this in mind.

Conclusion

With increased and earlier access to ART in a high prevalence, generalised HIV epidemic setting, stigma persists to frame PLHIV's experiences with HIV, and to shape their engagement with HIV treatment and care. Taking treatment and engaging with care presents both benefits and risks for HIV status concealment, which must be continually negotiated and navigated. PLHIV may be motivated to initiate ART early to remain hidden by avoiding the development of discrediting stigma symbols, i.e. signs and symptoms of HIV. However, engaging with treatment and care itself presents risks of exposure at multiple points, and for some this risk was deemed too great, with decisions to abandon treatment and care being described. Where individuals are engaging with treatment and care as a means to hide their status, this is likely to be fragile, with the risk of non-adherence or disengagement from care.

These findings point to the continued need for efforts to address the root causes of stigma and stigmatising processes where those with HIV are labelled with harmful judgements of difference, deviance and immorality. Regular measurement of community HIV stigma index could be beneficial, and programmes should ensure individual PLHIV are ready for treatment, have accepted their status and are not choosing to take treatment primarily to remain hidden, as this could undermine the sustainability of their engagement. Addressing HIV related stigma is crucial for the success of Treat-all, and should thus be a core component of HIV responses.

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