Understanding the Seriousness of 'Self' Identity and Changing Process of HIV among Zambian School Teachers Living with Antiretroviral Therapy (ART)

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Identity is often told through socially positioned narratives that take a biographical approach. Biomedical studies, though, tend to portray the 'self' of people with chronic illnesses from the physiological and clinical perspectives of effective diagnosis, treatment and care. Such perspectives may not provide adequate models for people with chronic illnesses to theorize, perform and live selfhood. The aim of this paper is to explore ways through which HIV positive teachers position themselves in their representations of life on ART, and important framings of identity that emerge. Semi-structured interviews with 41 HIV positive teachers (20 women and 21 men) in Zambia aged between 25–55 were conducted in an attempt to explore narrated sense of 'self' for individuals with HIV and on antiretroviral therapy (ART). A thematic analytical approach on different issues was employed. The ART practices around HIV were associated with, for instance, positionings within a supportive biomedical citizen-state contract around HIV treatment, in relation to de/professionalisation, in relation to 'accepting' or resisting lifelong medication. Positionality of the self -identity of living with this treatable though not curable virus, showed some high level of convoluted sense of being and representations of everyday lives on ART. The overall argument here is that identity issues among HIV positive teachers in Zambia appear to be influenced by the importance of community-based health care, by past experiences and present events, and by ongoing uncertainties about their desired futures. Further, the results show that ART is transforming and not removing HIV stigma related issues. Fragmentation and entanglements of identity under contemporary biomedicine and biopolitics seem to shape how HIV citizens live and self-identify. The research uncovers the need for enhanced social support and community-based health care systems in Zambia which will change attitudes and improve self-esteem for people living with HIV, such as the participants of this study.

Keywords: *acceptance, ART, identity, HIV, social, stigma, teachers, Zambia*

Introduction

From a health perspective, there is an increasing belief that people who receive treatment can live perfect lives or return to their 'normal' previous roles, even though the individual's entire life pattern may offer degrees of increasing incapacitation, pain and deterioration (Pallesen 2014). This experience of diminishing health related quality of life in turn creates a new form of identity from the previous state of health, with wider psychosocial implications in the context of identity and health interact in complex and changing ways, and especially through long-term health conditions.

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The core research question for this paper is: How do HIV positive teachers position themselves in their representations of life on ART, and what are the implications of these framings of identity that emerge?

The collective level of societal influence and the agency of an individual such as a teacher, depends on personal health and capabilities. It is now particularly important for the research focus to shift towards more qualitative (rather than quantitative) empirical explorations, in order to describe in depth and understand how people living on medication are finding the meanings of their chronic health condition.

However, research on the impact of chronic illnesses has mainly dealt with how specific disease conditions have been hampered by some health measures or the performance of activities of everyday living, rather than being framed within the context of identity. Studies suggest that people undergoing treatment do establish new forms of identity associated with the disease (Larsen 2016: 70, Gois et al. 2012: 34). Generally, the central ethical component in any biomedical model is the clinical diagnostic search for abnormalities, without any consideration of the medical implications for social, political and economic normality. As Nye (2003: 120) suggests, 'diagnosis [in medicine] defines the boundary of the normal', but these boundaries are malleable and subject to socially constructed interpretations. This implies that medicalisation shapes how individuals and groups make sense of institutionalised practices within socio-political structures. Thus, the process of laying down the boundaries of pathology and norms in bodies and behaviour is a social construction, albeit influenced by medical discourse and determinism (Turner 2000).

Identity involves claims, beliefs and processes about and of personal and social cohesion that inspire action (Mulubale 2017). The context of the research on identity described in this paper is the affirmations of group or individual particularities and desires for belonging, power and recognition (Parker 2005, Woodward 2003) that occur alongside chronic illness. Any potential fixed sense of identity, tied to specific states of health, illness and disease, is disrupted by chronic illness, which also produces more fluid notions of the self (Mulubale 2019a). This study will focus on identity because we are interested in the way in which structured roles can render the self-vulnerable, socially and professionally, in conditions of chronic illness.

The above understanding of identity is related to stigma and self-perception, though not key concepts of this study these need to be described. On one hand, stigma is the as applied here signify the ways that shape how friends, health workers or communities treat people living with HIV (Flowers et al. 2006). On the other hand, the theory of self-perceptions is utilised in the context of knowing how participants understood themselves first as individuals living with HIV and on ART, second as teachers with social networks that shape roles, attitudes and expressions which can also be influenced by external spill-over effects (Dagli-Hernandez et al. 2016). The theory of self-perception is connected to stigma because it influences the manner in which people understand themselves, their identity and others.

As earlier indicated, this study is on Zambian teachers who are living with HIV. Why Zambia and why HIV positive teachers? Zambia is used here because the country is part of the Sub-Saharan region, which has the highest rate of people living with HIV and on ART. Also, because Zambia represents about 4% of the world's people receiving antiretroviral therapy (UNAIDS 2015). Justification for working with/in Zambia is around the difficult of HIV 'citizenship' and development implications of a largely managed HIV epidemic in low/middle income countries such as Zambia – which has been unclear in literature and contradictory in scholarly debates. At present Zambian teachers as a target population of this study offer an illustrative analytical framework because they constitute an interesting but also complex group with diverse needs and privileges. With regard to working with teachers, though there is 'conceptual' justifications, interest in this sample also draws from teachers being a risk group which was highly hit by HIV pandemic in the 1990s and middle 2000 – due to enjoyment of a level of social status, mobility and school deployment away from spouses (Kelly 2000, Carmody 2004).

The multiplicity of identity in biomedical processes leads to the categorisation of populations. For instance, being HIV positive can lead to a clustering of personal feelings of self-esteem and social co-constructions of identity that emanate from spaces such as schools for Zambian teachers on ART (Cast and Burke 2003, Munachaka 2006, Flowers 2010). In politics, the dynamic consequence of shared societal values is capable of inducing another sense of nationality called 'ethnic citizenship', whereas in biopolitics it can generate what we refer to here as therapeutic citizenship (Nguyen 2008), as discussed later. The notion of biopolitical identity and its linkage to various forms of citizenship is twofold: first, the transition from awareness of individual illness to health consciousness; second, the move from a specific disease to the formation of a group membership based on similar treatment regimens (Collyer 2015). In this view, identity is both a process and an outcome of deeply felt personal illness and public health records that give meaning to biopolitical and social life (Wahlberg and Rose 2015, Whyte 2015, Nakata 2013).

The extent to which an HIV-citizened person can develop either a positive or a negative attitude towards their own identity is shaped by resisting the normalisation of HIV amidst effective ART. That is why addressing people based on their biological condition in some communities is seen as stigmatising, discriminatory, shameful and undesirable in the search for social harmony and mental wellness.

Using a social identity perspective, this paper unpacks the elements that shape narratives of selfhood among individuals diagnosed with HIV in Zambia. The foregrounding in this study of this concept – identity – makes up a significant part of this article's theoretical framing and analytical approach.

Having situated the central concept above, the next section will start by describing the methods and justifying their application in conducting and analysis of this study. Second, the findings of the research are explicated using a thematic approach. Third, a discussion of the findings is given arguing that HIV

representations are an identity issue which brings together a sense of difference but also offer new possibilities for better and healthy lives.

Methods

Research Strategy and Design

Qualitative approaches of research strategy were followed in this study. This study employed a broadly descriptive design for fieldwork, which involved semi-structured interviews to access current representations of living on ART and with HIV in Zambia. The choice of a descriptive qualitative design was rooted in the need to elicit detailed and wide-ranging data about the little-investigated and little-understood effects, across people's lives, of living long-term with HIV and ART in the global South, specifically in the context of maintaining professional employment at the same time. This descriptive process was achieved by being non-judgemental and non-interventionist in obtaining data, and being as comprehensive and close to participant representations as possible in data analysis, which started with micro elements thematic analysis (Braun and Clarke 2013, Bryman 2016). This study is qualitative and uses a descriptive design, as it empirically engaged Zambian teachers' representations of their experiences of HIV.

Participant Recruitment

Participants were also selected on the basis of their being in work and living at home but not physically frail. It is important to note that the demographic categories – gender, age, teaching years, qualifications and location (Table 1) – were all collected at the end of the interview, so that these categories were not foregrounded to participants as significant for the research, at a time when researcher had no means of knowing their significance, if any.

Study Population

The tabulation of the sampled population is as follows: Forty-one HIV positive teachers (21 men and 20 women) aged between 25 and 55 who were from both urban and rural localities. Most of these had served as teachers for average number of 5 years and more. Sixteen had a diploma education qualification. Also, 16 had late diagnosis, mostly when they were very ill and are now on continuous ART therapy. Thirteen participants have been on ART for 10 and more years. Also, there were 24 participants who had late diagnosis of HIV but continue to live health lives, hence ART is increasing longevity and health. Table 1 shows some demographics of the participants.

Table 1. *Demographic Characteristics*

Gender	Age				Location		Education			Years of taking ART			Diagnosis period	
	>20	>30	>40	>50	Urban	Rural	Cert.	Dip.	Deg.	>1	>10	>20	Early	Late
Men (n=21)	2	9	9	1	12	9	2	16	3	16	2	3	5	16
Women (n=20)	0	8	11	1	8	12	0	20	0	12	4	4	12	8

Collection and Analysis of Data

Fieldwork for this research was done between May and September 2017 under a commonwealth scholarship programme. The researcher is a Zambian scholar who at the time of working on this study was living in London. Semi-structured interviews that were used in this study lasted between 30 and 60 minutes with 41 HIV positive teachers from different localities of Southern and Western Zambia. The interviews were all conducted in English, which is the official language and medium of instruction used by teachers in Zambia. Questions in this research were open-ended but not too broad around key topics such as physical, psychosocial and material aspects of life on ART. These questions moved from the general to the specific, so as to strengthen arguments with not only information but also examples. The open question asked at the end gave the informants a chance to reflect, thereby (in)validating (most) ideas by participants previously discussed and perhaps addressing topics not focused on in the interview structure.

Coding transcripts in NVivo involved creation of categories derived from initial theoretical framing. Thus, the coding process was guided by the conceptual framework of identity. From the codes, the processing data moved to generation of themes which were supported by emblematic extracts from within the coded transcripts.

A combination of inductive and deductive approaches was used, to allow the themes to be determined by the data itself as well as initial theoretical frame. Aspects of the interpretation operated through distinct themes of interest with theoretical considerations of identity shaping all these different areas. The deductive analysis was guided by theory, in step six of Table 2, while the inductive approach was shaped by the interview topics, especially around steps three and four shown in Table 2. In the findings both theory and interview topics to some extent merged in the discursive section as to support key themes of the analysis. Therefore, findings are accounted for and results presented separately from discussions of the process of analysis.

Table 2. *Six Steps in the Analytical Procedure*

1	Transcribing of audio interviews
2	Transferring softcopies of transcripts into NVivo software
3	Creating codes in NVivo based on responses from interviewees
4	Looking for specific dominate categories that informed themes
5	Moving codes into categories
6	Generating themes that aligned with quotes, theory, literature and statements across the data

Thematic analysis of data was used in this study. This was primarily because it is a highly flexible framework of analysis (Braun and Clarke 2006: 78). The aim of this research was to identify patterns of meaning through six steps analytical procedure shown in Table 2. This process allowed for a complex and more diverse approach of understanding this study's qualitative data (Braun and Clarke 2013).

Ethical Consideration

Gaining ethical approval for this study involved submitting an application to ethics research committee of the University of East London. The researcher's role was to uphold confidentiality, anonymise responses as well as let the participants speak freely, to talk about their experiences with someone they were meeting for the first time. Full acknowledgement and adherence to the University of East London's code of research practice before and after being cleared to conduct this study, was ensured by the researcher. For example, any personal identifying information was removed from the data and quotes used here have pseudonyms. The ethics approval reference number for this study by the committee is *exp 1617 09*.

Study Limitation

The process of doing this study had some limitations. In the field, and due to the secrecy that surrounds HIV and living a positive life, some participants were very reluctant to sign the consent form before knowing the kind of questions they were going to be asked, and so they insisted on interviewing first then consenting later – such a contradiction. Two-woman interviewees did not feel comfortable with being audio-recorded; thus the researcher had to take down key points, with the limitation of not having the transcript to go back through what they had shared during the course of the whole interview. The research also does not claim to be representative of all HIV positive teachers in Zambia. They are accounts of individuals who willingly participated in this research. Therefore, caution in the interpretation of results and analyses must be considered.

Results

When responding to how they handled any effects of being HIV positive, the need to take ART and experiences of ART, most interviewees reflected on the principal reasons for their desire for survival and to live a long life. When they were asked about their life motivation; which related to how they dealt with their diagnosis and why they wanted to stay alive, the majority of participants' responses described their senses of survival which were based on aspects of relations with others (family and friends), occupational factors (teaching), educational advancement (going for further studies) and aspirations (desire for a better life in economic terms).

Otherness of Living on ART and with HIV

HIV and ART resulted in feelings of otherness for the majority of participants. Because awareness of being HIV positive constantly came into the mind, and was mentioned by 10 (24%) participants as making them think they were different. Many informants described how having a virus in their body made them develop a sense of otherness, as reflected in the comments by Mweemba:

> Mweemba (Man, 39): I feel different knowing that I am not leading a normal life. I know that there are some abnormalities in my life, so it makes me different. It is within me. A normal life is where I don't have to think at this particular time I have to take medication, I don't have to worry about taking alcohol, I don't have to worry. And of course, we are talking about the length of my life. Who knows what it would be if I was not in the state I am today. Talking of social life, one or two things I have refrained from. Beer drinking and just the way I interact with the outside. Of course, not to convey the message that this is my status. I have not told the general public my status.

It is interesting that participants described their actions and experiences of living with HIV and on ART so extensively in terms of people who are HIV negative. Although individuals made decisions and had the freedom of self-care (i.e., taking medication, avoiding risk behaviour and not missing doctors' appointments), it is the HIV negative individuals' stigmatising and socially isolating reactions regarding their condition that mattered.

HIV redefines psychosocial configurations in interpersonal relations and communities. For six participants, not having any family support had some negative effects on their mental and physical health. For example, absence of material support such as food led to some participants not having adequate meals which resulted in frail and visible side effects of taking medication without a balanced diet. Similarly, lack of family support can be associated with participants' own difficulties in acceptance, as found by Bond et al. (2016).

The use of 'we' by several participants in their responses refers to HIV social identity and group solidarity, which demonstrates that cooperative societies existed even before free ART access programmes. Contrarily, Mutukwa's words below clearly highlight the social complexity of interacting with others when one is on ART and living with HIV, from the local to the national and transnational. The quote below further illustrates how HIV status marginalises and stigmatises individuals.

> Mutukwa (Man, 39): Once people know that I am on ART, it becomes a problem. Let me give you an example. I might be in a group and pass a comment about a beautiful woman. If people know my status, they might remind me and say, 'you are HIV positive and so you are not supposed to think of sleeping with her'. If I ask such a person who told them that I was on treatment, they might say, 'I am just joking'. That would embarrass me, and I would know that people are talking about me. I think Zambia is not like other countries, actually the whole of Africa is still a problem when it comes to disclosure. If I disclosed my status to someone, they would tell other people about me, and I would be stigmatised. They would not even want to

share cups with me. […] I am not imagining [these things] are happening. I hear people telling each other that they should not give someone a cup because they are HIV positive. I have seen people being stigmatised. […] If I disclosed my status to someone, they would tell other people about me, and I would be stigmatised. They would not even want to share a cup with me.

Based on the extract above, HIV status is still a basis for marginalisation and stigmatisation for individuals or groups. It can be argued here that HIV disclosure is not a one-time event, but a process affected by medical factors and social relations. It seems time and physical place too can enhance feelings of stigma and experiences of discrimination. Self-reconstruction and non-disclosure in order to conform in various spaces were necessary for the majority of participants. Non-disclosure is part of stigma management of an HIV status, especially at work place, as reflected in Mbaeta's remark:

Mbaeta (Woman, 33): I do not trust some people. I think it will affect my work, because there are certain people who would tease me or something like that, and I would lose concentration at work. The problem is, we don't disclose to anyone. But there are two teachers who are also on ART who are very friendly, and we talk and chat.

The quote above reflects the difficulty of group solidarities due to anticipated stigma, and the possibility of socialising based on being on ART. For example, teachers generally project themselves as role models in society, yet being HIV positive is associated with stigma and self-stigma, breaking communal or social moral norms, and generating guilt about behaviourally acquired HIV, as noted by Sumbwa:

Sumbwa (Man, 39): Sometimes I am bothered. Because when I go to get medication sometimes, I don't feel welcome at the health centre. Sometimes when I go to the health centre, I get exposed to a lot of people, and some of the health practitioners do not understand me as a civil servant. This is because some of these people that give us medicine are just caregivers from the community. Sometimes they do not handle us very well. I get delayed by the volunteers because they do not understand that I need to get to work.

Encounters with HIV's otherness start at the hospital, as noted in the quote above. Being seen in open queues of those receiving ART drugs at the hospital, and needing time to get back to teach, adds to both the sociality and (de)professionalisation narratives about living on ART. Additionally, being served by volunteers during hospital appointments was pejoratively described here (and by other participants), as most of these community health workers do not have full medical or nursing training. Sumbwa presented them as non-professionals who were judging the lives of professionals, whom HIV had led them to deprofessionalise.

Both the continuous nature of treatment programmes and the need for social support generate distinct forms of identities. For example, we notice in the findings that at the start of ART, several participants who had adapted fast to the

treatment had had people who helped them through the transition to taking their medicine on a daily basis. Mudenda put family support first, despite prioritising religion:

> Mudenda (Woman, 39): I have selected some members of the family who have to talk with me over the same problem. If I happen to complain, they come and start interacting with me. But mostly I do get my bible and read. And telling my conscious that cannot reverse this situation, but I just have to move forward.

The quote above shows that seeking support from family is significant. Thus, peer groups - consisting of people living with HIV and from clinics by service users - can be alternative in the absence of family support. The need for acceptance from others was high, especially in the early stages of diagnosis when they were coming to terms with their status. In this regard, these results further support the idea that presentation of the self and identity manifestations in HIV is more relational than personal, as also found by Bond (2010) and Whyte (2014: 17).

HIV and ART Affects Social Bonds

The act of concealing and revealing the 'HIV self' is an aspect of stigma management manifested through social identities (Goffman 1963). To gain control over their health condition, participants demonstrated that they needed to monitor themselves in all groups and situations. However, uncertainty over how to manage a long-term medical condition also led to forging resilience through disclosure techniques that were useful, even in workplaces. Disclosing an HIV status to others gave participants a sense of control over their HIV and ART. Consider Sitondo's remark:

> Sitondo (Man, 42): My District Education Board Secretary told me to say these ARVs are just like food, so it is from that angle actually that I take ARVs as food. He used to tell me that food, you see, we take it on a daily basis, so there is no way one can feel stigmatised by self or others for taking food. So, it is that in that sense that I take ARVs as food. Even when I used to go for collection of medicine, I used to hide, but this time I just go openly. […] Because it is psychological. […] If I don't disclose and people start knowing about it, I would feel bad if I hear people talking about it. So, when people talk about it when I have told them, then it does not become an issue. So, it reduces its power on me. Actually, disclosure is a strategy, unless maybe you have a hidden agenda, that if I disclose women are going to run away, but I am already married, so I am not worried of that.

The above remark shows daily acts grounded in ART and directed towards an HIV identity – here, involving a workplace superior providing supportive advice – exercised in a workplace environment.

In order to avoid some external barriers to outwardly embracing an HIV image, co-construction of the self within social collective experiences is inevitable. It is during the reimaging process of self-identity that patients are able to normalise and socialise. The process of constructing a shared HIV image is situational, as

illustrated by Sitondo above. HIV positive teachers experience ART through solidarities and alliances.

Even though it is often done cautiously, the identification of individuals to talk to about an HIV positive condition is empowering. HIV solidarity among participants is about individual premonitions of disclosure. Hence, at the centre of HIV solidarity in the context of identity is trust, acceptance, and being aware that taking ART is not to be differentiated as a problem of others, as found by Bell et al. (2016).

It was clear that being HIV positive involved a lot of psychosocial issues that one needed to confront, and most of these were concerned with relationships. The extent to which participants felt and acted with courage was described in terms of social relations, as Likando put it:

> Likando (Man, 28): I was uplifted and encouraged to learn that I wasn't the only one who was on this kind of medication. When I first learnt about my status, I thought I would die soon. But when my family members and friends, those that had lived for a long time, told me that they have been on the treatment for many years, I realised I would also live long.

It can be seen in Likando's statement that self-identity among participants was at least partially informed by external social forces.

In the data, responses about life motivations or sense of need to stay alive were based on self-representations which differed across interviews. Self-imaging was reported in the light of HIV treatment by 15 participants, who retained a sense of self as largely being shaped by their biomedical condition. However, six described and related their self-image to relations but also attached their professional life of teaching to it. Only 11 directly mirrored narratives of themselves through relationships to family, children and others. More than half of the participants spoke of their personality and hobbies when they described themselves, for example as being humble, forgiving and playing sports. Only one participant was not sure how to describe themselves. Some of the above findings contradict minority of participants' views of identity being shaped by social networks.

What stands out in the above data is that representations of self-identity were equally shaped by external social forces and personal life conditions which may include one's profession as viewed by others and the role it plays in society. However, being a teacher was important to some, in spite of their HIV status. For instance, Pumulo (Man, 48) described himself in terms of being a father as well as a teacher, without bringing his health issue into the picture.

Responses about self-descriptions led me to ask further questions about being and feeling different due to ART requirements. It was striking to note that the majority of participants agreed that they were different from others who were not HIV positive. Only 17% of respondents said they were not different, but they gave reasons that would distinguish an HIV positive person as different.

Participants demonstrated that one was different from his or her previous life before diagnosis, and not the same as an HIV negative person, because of such factors as the following: stigma, spousal abuse, self-awareness of having an

incurable blood-borne virus, weak relationships and losing friendships, fear of ART side effects and death, extra care for a heathy life, as well as psychological changes associated with HIV status.

From the above, it can be noted that awareness of being HIV positive constantly came into the mind, and was mentioned by 10 (24%) participants as making them think they were different. Many informants described how having a virus in their body made them develop a sense of otherness which affected their social relations in either a positive or negative way.

These results reveal two divergent views. The first is that most of the interviewees tried not to see themselves in a different way from those who were HIV negative; second, they acknowledged that owing to ART their lives had a quite different approach from those who were not positive. In this regard, the findings suggest that factors that informants said were reasons for feeling and being different were related to biomedical and mental issues. Overall, it was this sense of being aware that one had a virus – 'something in the body' (in a comment from Nalu, woman, 31) – that impressed as the cause of uniqueness in relation to both one's former self and other people in one's communities, including in the school as a workplace.

Discussion

HIV Identity: Its Constructions and Life Altering Effects

It has earlier been noted that changes in behavioural patterns are associated with ART practices that have been socialised. Social identity changes take place within individual and collective social dimensions of interaction as mediated by medical factors in a given space and time (Tucker and Goodings 2018). Similarly, findings on self-descriptions suggest that medicating bodies is the basis of an HIV identity, self-concept and esteem, created mainly through clinical diagnostic categories of either physical or mental health issues, as shown by Tucker (2009, 2010).

Both negative and positive experiences at hospital reinforce an HIV identity. Self-identity in HIV is driven by medical factors played out through social relations. For example, daily ART management, state control of pandemic policies, and long-term provision of healthcare services make HIV chronic living intersect with community, as shown by Wahlberg and Rose (2015). Findings, such as fear of death and health uncertainty form part of living with HIV that reveal ART as having an identity effect on collective living with a chronic health condition.

The findings on social support reflect a biomedically driven story of identity. Although differently described, the social, political and physical 'health' of participants shared the same basis in living with HIV. Participants generally agreed that their free ART was a right, which also affirmed a framing of social identity driven by HIV. Although HIV identities appear medically fixed, they shift based on social and health fluctuations. For example, the subjectivities involved in

revealing a biosocial image informed by ART could possibly interfere with the way participants carried out their work.

Subjectivities involved in ART experiences can lead to testimonies of a shared identity narrative through medicalisation for possible support and integration. Thus, self-imaging for several participants was predicated on the psychological and social effects of being on ART, which mainly attracted shame and isolation, similarly to findings of Ho and Goh (2017). Also, being 'normal' is questionable for some participants due to their daily therapy to supress HIV and comparing the state of their bodies before the start of their ART, and also in terms of life without HIV. There is tension in syncing social and medical identities. From the findings, it can be maintained that those who succeed in maintaining relationships after an HIV diagnosis have to some extent disclosed and freely incorporated their HIV status in their social networks.

HIV identity provides an initial step to normalisation through disclosure. To receive support, a certain form of social identity needs to be established, recognised, and not integrated into mainstream cultural identity, which goes beyond family and friends to include the workplace and the whole community. Fear of being labelled 'different' and wanting to fit into the social fabric prohibits disclosure and predisposes some participants to self-exclusion.

From the quote above, being HIV positive and on ART can be associated with an internalised form of identity that can be revealed for group inclusion and even exclusion. It was this uncertainty that caused some participants to craft double identities: an HIV image embraced in private, and a professional public-facing image. However, the distinctiveness of populations such as those with HIV can be a basis for recognition through difference from the rest of a given nation.

In this regard, the notion of nationhood finds interpretation in HIV identities through support structures and the sense of belonging created by HIV citizenship. For example, reference to collective ownership of HIV through language, by use of words such as 'we' or 'us' in several interviews, resonates with how identity can be constructed around illness and used as a form of social world that represents a specific group. The need and usefulness of identifying someone for support by participants in their medicalisation process is fundamental for HIV identity.

Identity as a concept holds that differences among people are not only about class, race, gender and place, but also other factors, such as professional status and health condition, determine the degree to which individuals associate with groups and social cooperative formations (Harfitt 2015: 8). The interconnection between the socio-political and the pursuit of personal well-being can be attained through interactions from a health and illness point of view.

In the data from this study, there is a connection between participants' representations of their health condition and their framing of their social relations. The process of transitioning into ART is associated with various forms of representation, but representations of HIV identity outcomes differ based on gender. Eleven men in the sample said they had found it hard to socialise after HIV diagnosis, while women had easily extended social clusters with fellow women, especially those who were also on ART, as also found by Whyte (2014).

Therefore, emphasis on gender as the basis for social group formation and inclusion is high among women participants.

Decisions to collect HIV drugs from a more distant district hospital show the social relations of HIV stigma operating, even in this treatment era (Bonnington et al. 2017). Not wanting to be known to be on ART by neighbours forced some participants to seek treatment in faraway hospitals where they were not resident and not known.

For the majority of participants, identifying some individuals as supportive, and telling them about their diagnosis, helped with adhering to ART and promoting good health practices. Continuous active involvement in social networks of family and friends was key in enabling some participants to test, start treatment and manage a life that was reliant on ART – including through group programmes and peer support. The use of the term 'member' of an HIV sociality is more appropriate than 'client' of an HIV service (Whyte 2014), because 'membership' as opposed to 'clientship' helpfully highlights not only service dependence or utilisation but also important personal relations; the normalising effect of recognising oneself as a member of that sociality.

In the statement above, a sense of normalcy when diagnosed with HIV is situated as an identity and social interaction issue. The normalcy of 'staying healthy' with HIV which implies avoiding opportunistic diseases and adhering to good behavioural practices as well as medication, and the awareness of having a virus, have some underlying intensely social, profession and/or asocial features.

Two things can be noted from the findings. First, it is necessary to have a *mind* (not just a body) that conforms to what society prescribes as normal in order to be considered 'healthy' and not 'ill'. Second, illness is defined by the collective actions of society that specify 'normal', and any deviation from that is deemed as 'illness'. Also, for most participants being or feeling 'normal' through ART is not only a biomedical issue, but also psychological and social aspects which entail absence of mental, physical and relations discomfort.

Identifying others who are also living on ART initiates the process of socialising for individuals and in groups. HIV identities are strengthened by location and gender demographic factors. Reflecting on the self as being different and/or similar to other citizens begins with an awareness of being HIV positive and knowing members in the locality who are on ART, especially through the hospital. Therefore, at the centre of the formation of social groups and the development of kinship ties based on HIV is location, which provides physical spaces for interaction around the diagnosis. The gender dimension of sociality is seen in women's cooperative responses to individuals in a school. Although woman participants associated in groups for recognition, men interacted cooperatively due to biosociality, albeit mainly in secret.

Social class has a direct effect on how HIV identities manifest themselves, as participants formed a sense of self-identity around their diagnosis through their status, economically and socially. There is an association between participants' middle-class status and aspects of social actions that relate to behavioural changes and good health practices. This class-related finding, and its connection to health, is similar to results found by Marmot (2015). HIV medicalisation affects the

immediate social relations of people living on ART and others. This finding on HIV teachers' solidarities has not been explicitly covered in existing research.

Being on ART is and can be used as a criterion for the struggle for acknowledgement, inclusion and respect by those living an HIV positive life, such as teachers in schools. The underlying effects of medicalisation among professions, such as teachers, which continue to limit their abilities to fulfil their role in embodied capital investment by improving acute health problems yet ignoring chronic health difficulties such as iatrogenic disease, bodily pain and constrained socialisation as well as restricted involvement in any physical intensive work, would still lead to a huge demand for private and public interventions to sustain social and economic reproductive activities (Mulubale 2019b).

In addition, improvements as well as crises in a person's and a population's health often have the greatest effects on socio-economically vulnerable groups, such as teachers, who have low wages and are under public scrutiny in society (Brentlinger 2018). Healthy individuals also contribute to the good health of those around them, because they do not become disease burdens, but instead look after others (Marmot 2015, Sachs 2002).

The demands of ART and social reclusiveness are connected. HIV disclosure is to a large extent a source of group formation through mutual recognition by those who are also HIV positive. Additionally, identity aspects in HIV reveal that the institutional setting and social relations of living on ART play a critical role in the disparity of outcomes in relationships, professional networks and competencies, as shown by Whyte (2015).

HIV communities can be established and sustained by an overarching political structure that creates a sense of nationhood. Findings on support suggest that ART has some organising effect, through self-help strategies and larger group strategies; for example, those who are HIV positive may systematise themselves as being one people. This finding that – they are 'one' in the opinions of participants – differs from other studies (Lock and Nguyen 2018, Camlin 2017) that found a more individualised than collective sense of HIV identity and care.

Identity formation is a continuous and not a fixed process in HIV, due to ART demands as well as fluctuating health statuses. The results of this study show that social life is changed after an HIV diagnosis and throughout treatment for most participants. These changes involve reduced peer interaction, reordering of social activities due to being confined, reductions in the size of friend networks, and intensification of close relationships with others who are also on ART. The physical health of participants was a basis for social life changes and the reorganisation of networks of peer groups and allies to include medical aspects, as also found by Whyte (2014).

From the above, it can be contended that HIV identities remain socially situational, institutionally absent and medically subject. Most of the HIV otherness factors identified in this section are related to participants' ART experiences in the past, present and future. When living with HIV, people carry the past with them, and become concerned about themselves in the present and also their future selves. Biological differences related to an HIV diagnosis are essential in the social connections of therapeutic citizenship in the long term (Mulubale 2019a).

ART Transforming but not Removing Stigma

This study found that disclosure was not a one-time event, but a continuous process that was problematic. The theme of stigma and acceptance in the findings relates to issues around disclosure. There are two things that emerge on this topic. The first is that only seven participants who were not thereby seeking support disclosed voluntarily, indicating the situational process of disclosure. Second is the idea that those who feared to be stigmatised disclosed only involuntarily due to circumstances, and also that they had high levels of self-stigma through anticipation of negative disclosure outcomes. This finding on involuntary disclosure seems not to have been explored in previous studies, whereas the results on voluntary disclosure are similar to findings by Bond et al. (2016) and Lyimo (2013: 102).

This study found that stigma in HIV care and treatment has only changed but has not been eradicated, as found by Bonnington et al. (2017). It found, though, that ART was said to have largely eliminated appearance factors associated with stigma by improving physical health.

Explicit questions about disclosure led to responses about the importance of opening up to family, friends and medical personnel, and factors that played into the decision to do so. This finding suggests that people who are HIV positive are now able to consider and predict successfully the effects of family disclosure, as shown by Camlin (2017) and Van der Sanden et al. (2016). In the absence of anticipated social acceptance, participants reported travelling to distant hospitals and always hiding their ART pills, as shown by Elwell's (2016) study. Responses on spousal disclosure were one-sided, as women but not men reported disclosing their HIV status to heterosexual partners, a finding which other studies (Bond 2010, Henning and Khanna 2016) do not mention.

Disclosure made it possible for participants to join HIV communities and created a sense of belonging, as described by Camlin (2017: 4–5). It also appeared that participants who were public about their HIV status had limited adherence difficulties, for instance having the possibility of getting reminders from others to take medication, as found by Bernays et al. (2016) and Kim et al. (2017). Also, disclosure was a strategy for avoiding gossip and embarrassment and having peace of mind, as also shown by Bell et al. (2016) and Bond (2010). Self-isolation due to HIV shame was reported as a key reason for non-disclosure, depression and social withdrawal, similar to findings by Ho and Goh (2017), Hutchinson and Dhairyawan (2018), Vincent et al. (2017) and Wong et al. (2017). These results are distinctive, because they show disclosure as a process and not a one-off event. It is this continuum of disclosure that makes participants anxious about their status, making it an internal and mental health issue that can either be beneficial or be associated with a lack of self-confidence and acceptance of living on ART.

The majority of participants described poor interactions with health workers during ART drug refills as a stigma issue that starts in hospitals – a striking finding at this point in the epidemic.

Conclusion

Identity in ART practices are entangled in social elements of HIV through such factors as stigma. The findings have shown that social difficulties associated with HIV cannot be eradicated by ART effectiveness only. The medicine cannot be the only basis to 'normalise' HIV chronicity, without considering its high mortality legacies and treatment exceptionality in African nations. Hence, the decolonisation of knowledge on identities that relate to HIV here is embedded in the relationality of HIV management, through references to an awareness of interdependence and integral relationships amongst participants in the community of which they have become part. This relationality is about the search for balance and harmony while living on ART and with HIV.

The act of (dis)entangling the psychosocial factors within the HIV community signifies the process of decolonising real (space), imaginary (power) and symbolic (knowledge) attachments to ART (Mignolo and Walsh 2018, Masing 2018). That is why HIV identity narratives, as framed here, refutes the perception that HIV experiences are universal. The findings show that normalisation of ART has a Western origin which describes the global but neglects the local elements that are relevantly attached to ART adherence successes. This study recommends that attention should be given on the importance of undoing medical narratives of HIV normalcy and totalising claims about ART legacies or practices based on pharmaceutical knowledge underpinned by biopolitics and geopolitics.

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