# School Teachers' Health and 'Therapeutic Citizenship' in Zambia: Problems and Prospects

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# Abstract

A treatable illness, HIV (Human Immunodeficiency Virus) has both latent and visible psychological, social and economic effects on infected and affected individuals. School teachers as a key population and large civil service workforce in Zambia, appear to have distinct representations of HIV citizenship and ART (Antiretroviral Therapy) experiences. This study employed a qualitative and thematic analytical approach to examine the notion of therapeutic citizenship as represented by school teachers in Zambia. The aim of this paper is to explore ways through which HIV positive teachers position themselves in citizen experiences of living with HIV and on ART, which are important framings of 'therapeutic citizenship'. Semi-structured interviews with 41 HIV positive teachers in Zambia aged between 25 and 55 were conducted. Transcripts were processed using NVivo Pro 12®, following a thematic analytic methodology. The results show that gender, location, social and professional life play a role in how HIV-citizenship is represented and appropriated. The unending treatment practices around HIV can portray individuals' self-narratives as 'resistant' subjects by, for instance, describing them as victims of 'pharmaceutical colonialism' in Zambia. Findings suggest that identity entanglements and fragmentation of selfhood in biomedicine and biopolitics seem to be a pivot for critical citizens, such as the participants of this study. HIV programmes must be aimed at people in Zambia who know little about some newer aspects of HIV treatment which if known about could be destignatising for people who are negative and positive and could help reduce incidence for younger and older people.

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#### Introduction

There is a growing understanding of the association between citizenship and biology (Lock and Nguyen, 2018). However, the medical, psychosocial and material factors that determine therapeutic citizenship have received little attention and limited understanding by scholars in the social sciences and biomedicine. Using a psychosocial perspective of HIV and citizenship, this paper unpacks the conceptual and empirical elements that influence living on ART and HIV for key groups such as teachers in Zambia.

The article is divided into three sections. First part gives some background information and a rationale of study through a review of literature. It also addresses the conceptual positioning of therapeutic citizenship in the study and methods, second it highlights the key procedural steps that were followed from participant selection, interview process to data analysis as well as ethical consideration. Third section gives the results and discussion. In the conclusion and final analysis, the paper makes a proposition that HIV citizenship in Zambia is larger and marks a defining role in 'non-HIV' aspects of people's lives but does not reduce them to it -within a 'therapeutic citizenship' context. In the section that follow, we begin by situating some background information and review of literature.

HIV citizens, at least in Zambia, do not often act and mobilise on their right to health – embedded within political citizenship – hence likely not to place health related demands on the state (Mulubale, 2020; Whyte, 2012; Patterson, 2015). Given the assumed socio-economic implications of the pandemic, there is no scope to escape the long-term treatment adherence necessities of HIV citizenship (Young et al. 2019). The notion of therapeutic citizenship is useful, as it allows resource needs, unrecognised phenomena to be named, described and brought into collective claims (Petryna, 2004; Nguyen, 2010). For example, both Mattes (2011) and Marsland (2012) show the elements of therapeutic citizenship in their studies on Tanzania by focusing on the importance of sociality and location as key in enhancing forms HIV support in communities especially among women. The gendered perceptions of HIV health experiences found in these studies above is an element of therapeutic citizenship.

The broadening space of HIV treatment seem to be increasing ART effectiveness outcomes and vulnerability among people living with HIV and are on medication (Persson and Newman, 2006). An ethnographic study by Ware et al. (2009), demonstrates that adherence issues in Nigeria, Tanzania and Uganda had a citizenship commonality. For example, adherence success reports across these countries were found to be associated with help received from partners, friends, family and health personnel. This collective way of insuring ART adherence by participants is part of the citizenship expectation of helping others and being helped when need arise, which produce a sense of responsibility (Steenbergen, 1994) to adhere to medication for those living with HIV. Evidence by Whyte et al. (2013), suggests that the idea of 'belonging' when HIV positive is a citizenship issue as it involves ways of living. Nonetheless, the ART landscape is now more about clientship than patient - that reinforces a sense of care and sometimes being different from other citizens. It is the differences among citizens that produce HIV micropolitics especially around treatment and care in countries like Uganda, where the nature of HIV citizenship in the clientship sphere of ART is framed by social networks that are cultivated through access to health programs and other benefits. Whytes and colleagues' study confirms that HIV is about therapeutic clientship that is related to roles of the state and ideas of political belonging when living with a chronic condition. This approach of focusing on therapeutic citizenship has not been explicitly explored empirically in the global south.

Therapeutic citizenship is a central concept of this article. Therapeutic citizenship here is conceived as relationally shaping understanding on the politics of chronic conditions in this treatment era. HIV has transformed societies as it is a global issue with long-term health implications tied to taking medicine; every day and on time, for life (Paparini and Rhodes 2016; Mulubale, 2019). In this view and based on the conceptual context, HIV positive teachers do experience some 'on and off' episodes of wellness and illness both physically and mentally (Rooks-Peck et al., 2018) but how this affects their roles in schools is explored based on empirical evidence of this study.

With the above in mind, 'therapeutic citizenship' is a phrase that highlights the biopoliticisation of populations and the self-management of bodies, especially in illness, which involves claim-making through local and international channels (McDonald et al., 2016; Nguyen, 2010; Rhodes and Paparini, 2016; Whyte, 2013). Additionally, Patterson (2015:1) defines therapeutic citizenship as 'biopolitical membership that includes claims and ethical projects that emerge from techniques to control and manage bodies. Embedded within this understanding of therapeutic citizenship by Patterson is the idea of medicalization, used here to denote a process of sophisticated medical treatment among citizens, that allowed fewer and fewer things to escape (Bulley, 2014; Foucault, 2008). To explore participants representations, a qualitative approach was employed.

# Methods

## Study population

We conducted semi-structured in-depth interviews with 41 HIV positive teachers from different localities of Southern and Western Zambia. 21 were men and 20 women. These participants were aged between 25 and 55. Since the aim of this study is to examine and rethink the aspects therapeutic citizenship within an HIV context of experiences of the teachers who are living with ART, a qualitative approach is the most suitable. This qualitative approach allowed the author to understand the social and medical phenomena of meanings by participants and gained insights about their representations of living as HIV citizens.

Why Zambia, and why HIV positive teachers? Zambia was 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, Zambia represents about 4% of the world's people receiving ART (UNAIDS, 2015). The justification for working in Zambia is therefore around the difficulties of HIV citizenship and the development implications of a sizeable but largely managed HIV epidemic in a low- and middle-income country such as Zambia – issues which have been investigated only to a limited degree in scholarly debates (Kelly, 2000). Zambian teachers as the target population of this study constituted an interesting but also complex group with diverse needs and privileges.

Gender	Age			Location		Education			Teaching years			Diagnosis period	
	>20	>30	>40	Urban	Rural	Cert.	Dip.	Deg.	>1	>10	>20	Early	Late
Male (n=21)	2	9	10	12	9	2	16	3	6	10	5	5	16
Female (n=20)	0	8	12	8	12	0	20	0	7	6	7	12	8

Table 1: Participant characteristics

From table 1 above, the tabulation of the sampled population is as follows: 41 HIV positive teachers (21 men and 20 women) aged between 25 and 55 who were from both urban and rural localities. 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 – 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 we had no means of knowing their significance, if any.

# Data collection and analysis

Findings of the study were generated through semi-structured interviews conducted between May and September 2017. The study utilised one-to-one and each interview lasted for a period of 20–50 minutes, usually without a break, although participants were free to take a break at any time. A question guide was followed, although the

order of asking questions was not important (Patton, 2002). The interview schedule did not try to be exactly the same for each participant, but aimed to follow what each participant talked about. The interviews were conducted in a distraction-free place that participants preferred.

Questions in this research were open-ended but not too broad. These questions moved from the general to the specific, so as to strengthen arguments with not only information but also examples. Interview audio recordings were transcribed manually. The interviews were transcribed word for word. Transcription allowed isolation of brief segments of excerpts from conversations (identified here using pseudonyms) that were important in the different areas of analysis. By coding the responses manually in NVivo, some of the transcript excerpts were coded to more than one category of themes. Therefore, findings are accounted for and results presented separately from discussions of the process of analysis.

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). Since one of the interests of this research was to identify patterns of meaning, thematic analysis as a method was the most appropriate approach for this task, because it describes and organises the data set in extensive detail, and even captures different topical issues beyond the study objectives, allowing for a complex and more diverse approach of understanding qualitative data (Braun and Clarke, 2013) in an inductive, bottom-up way as well as analysing them in a more deductive, top-down way in relation to existing literature. Aspects of the interpretation operated through distinct themes of interest with prior theoretical considerations shaping all these different areas. Entering material into NVivo in categories, made the analysis start out very descriptively and broadly; it then became more narrowly thematically organised. This progress raises again the important point that even the initial thematic analysis was not purely inductive but was a dialogue between bottom-up and top-down approaches, which was how the findings were generated and data was managed.

## Ethical consideration

Ethics approval was gained from the University of East London, United Kingdom. Permission to conduct research was sought from District Education Board Secretaries and Headteachers of schools as well as community-based workers as gatekeepers. Participants were first given details orally on the aim of the whole study and then provided with information sheets and consent forms to sign beforehand. They were also informed and assured of confidentiality by not asking about their person details or identifying information and they were free to withdraw from the study at any time. The names or quotes used in this paper are pseudonyms. A risk assessment for fieldwork was done before obtaining clearance from the aforementioned university's ethics committee.

#### Results

#### Participant characteristics

From the demographic data shown in table 1 above, there are several cross-cutting issues that can be noted around age, period of being on ART, teaching period, location (rural or urban), gender, and some level of education qualification. For example, the gender distribution was proportionally equal. Although some men-teachers were reluctant and delayed showing an interest in participating in this study, they had an extra representation of one, making the sample tabulation 21 men and 20 women. The majority of the women teachers in this study were teaching at primary and lower-level tiers of Zambia's education system, whereas several men recruited were from urban areas and were working at secondary schools, getting a higher salary with relative access to medical facilities.

This is descriptive data which shows that more women than men had early diagnoses. Twelve out of 20 women had tested for HIV much earlier, compared with five of 21 men. The variance between men's and women's diagnosis periods suggests that women went to test earlier after infection, without any signs of physical illness, whereas men waited until they were sick to be tested and treated. Also, women's being long-term survivors of the pandemic meant that they got tested and commenced on ART as a consequence of either spousal death or antenatal visits for would-be mothers; this discrepancy is discussed in detail later. The years of teaching experience ranged from one to over 20. Most participants who had taught for more than 20 years talked of wanting to change their job from teaching, with six even discussing retirement after teaching for a long time.

#### Long- and short-term experiences of ART

There was evidence that ART had an influence on informants' lifestyles. There were some negative and positive comments about the complex challenges of being treated for HIV. Although each participant's view varied across space and time, the majority of participants mentioned experiences that were similar in many ways. The results obtained were mixed between long-term and short-term effects, in relation not only to ART but also to the impact of being HIV positive.

Moola (Man, 51):

#### Table 2: Positive and negative effects of ART

Experiences of being on ART	Women (n=20)	Men (n=21)	Total (N=41)
Negatives			
Nightmares	4	2	6
Memory loss	4	2	6
Body changes (weight gain, skin and fertility)	2	1	3
Moods	3	2	5
Dizziness hours after taking pills	10	7	17
Daily frequency of dosage is hard	6	2	8
Schedule of taking and collecting drugs is hard	1	5	6
Curtailed travelling (carrying medication is problematic)	3	4	7
Positives			
Improved physical health	2	2	4
Increased appetite	2	0	2

Within the findings there were positive and negative experiences, in both the short and long term. Health recovery was mentioned as long term but positive. What is profound in the results shown in Table 2 is that 41% (17 respondents) experienced some dizziness every day and right after taking the medicine, lasting for at least an hour. The dizziness was reported to be disruptive, as it meant a period of inactivity until their reaction to the medicine stabilised. Moola described the aftermath of daily dosage:

After taking the drugs I always feel dizzy for the next one hour, after taking one sleep. [...] When I take the drugs and I'm feeling dizzy, I chat with my wife to just unwind and forget about how I'm feeling.

Taking pills every day at the same time was considered problematic by at least 34% (14) of the respondents. This is rather a significant result, as it reflects that some participants found it hard to take a pill every day for as long as they lived, without any hope of a cure. Alongside the daily dosage was the issue of quarterly clinic appointments to refill medication, which was seen as a burden by some interviewees. Talking about this issue, one interviewee said: Sikota (Man, 52): I find it challenging sometimes to go to the hospital every three months and taking a

I find it challenging sometimes to go to the hospital every three months and taking a drug every day. If there could be a drug that can be taken every six months instead of every day.

It was unforeseen from the data to observe that six informants grappled with loss of memory, which they said was a side effect of ART. Some interviewees mentioned that they found it difficult to remember things – for example, when to take medicine, and forgetting to teach some aspects of their lesson plan as teachers. There were some negative comments about physiological changes due to ART. It was suggested by some participants that problems such as weight gain, erectile dysfunction, reduced libido and infertility were caused by HIV treatment. Indeed, Sitondo reflected on his bodily changes, stating: Sitondo (Man, 42): There is one thing I have observed. [...] My erection has reduced. So, I have been

There is one thing I have observed. [...] My erection has reduced. So, I have been having a feeling that maybe it is related to the drug. Some have said yes, others say no, it's your weight.

Being HIV positive was said to have weakened relationships and reduced levels of intimacy among spouses, by both men and women. This was related to experiencing uncomfortable weight gain by over half of the participants, while Sitondo's story above outlines how his weight gain (supposedly from ART) led to erectile problems. It was also common among participants to believe that antisocial moods were associated with ART treatment side effects and were a long-term negative experience of being HIV positive.

For a small number of respondents (six), starting ARVs was a reason for sleep difficulties, including nightmares and sweating, which were short term as they lasted from days to months. For example, Beenzu described her experiences at the start of ART:

Beenzu (Woman, 46): I just got tested and was given medication and told about the side effects to expect. My

experience in the first three days was bad because I was bedridden. [...] After a month, I started gaining my strength. The first month was difficult because I had a lot of side effects.

We can see a commonality in these findings from Table 2, at the start of medication, physical fragility got worse, and adherence was hard within the first days and before the regimen was stabilised. This suggests that time plays a role in the effects of ART on long-term and short-term medical outcomes. Both positive attributes of having the chance to live longer and overwhelmingly negative experiences of being HIV positive were reported.

## Managing the effects of being HIV positive and living on ART

Some negative experiences in participants' responses cited above surfaced in relation to how they managed to live

Nalu (Woman, 31):

Mutukwa (Man, 39):

with the virus and on ART. Some interviewees argued that it was through knowing about self-care techniques, while others held the view that social factors were useful in their quest for a healthy life.

It was interesting to note in transcripts that 11 (27%) participants mentioned the issue of keeping themselves busy – for example, belonging to faith groups, which was discussed in relation to belief or religion as a form of strategy to overcome HIV challenges. When asked about how she mitigated some of the hardships caused by the treatment she was receiving, one participant stressed the importance of being active:

Nalu (Woman, 31): Keeping self-busy and not focus or thinking of the bad part. I have to keep myself busy. Mostly it's teaching and talking to other people.

Twenty-nine per cent of participants agreed that physical exercise and eating nutritious food were important for immunity-boosting despite being on ART. However, few talked about being able to exercise or following a balanced diet. Acceptance, both from others and from oneself, was significant in the management of HIV, especially after diagnosis.

In the data, responses about motivations 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 primarily based on their professional life of teaching. Only 11 directly mirrored narratives of themselves through relationships to family, children and others. Of all the participants, only 25 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.

What stands out in the above data is that representations of the self were equally shaped by external social forces and personal life conditions such as being a teacher and living with a chronic condition that required daily treatment. However, being a teacher was important to some, in spite of their HIV status. For instance, Pumulo described himself in terms of being a father as well as a teacher, without bringing his health issue into the picture. Pumulo (Man, 48): Having a family motivates me greatly, it makes me so happy. I am a parent and a very

happy husband, and of course finding myself in the teaching fraternity. I am a teacher currently handling computer studies at junior level. It really makes me proud of myself.

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.

Despite reported improvements in physical health after starting medication, the body in several accounts was regarded as vulnerable and limited. Overall, 22 (54%) respondents commented on medicinal uncertainty, which they said was the source of constant worry regarding treatment failure on one hand, and the sustainability of the government supply of the pills they were taking on the other.

ART experiences reported by participants confirmed the distinction between hope and uncertainty. Some felt that the medication gave them hope, while others considered that the lack of cure was a concern and a source of anxieties whilst on ART. Thus, Nalu's comment below illustrates many responses that were contradictory but pointed to concealed ART hardships that were physiological and psychological experiences:

Just that living with a virus every day is a challenge, I can't deny that again. Maybe I will contradict myself, but there are times, like I was saying, I can't say I am a normal person like the other person, I have got limits, what the other person can do, me I would say, if I do that maybe I would weaken my body. I have to keep my body like this, I have to keep my body like this.

The emphasis placed on the protection and preservation of the physical body to keep it 'like this' and be able to carry out daily routines was contradicted, for example, by reports of side effects from ART that damaged the liver over the period of time of taking the drug. Eight participants emphasised the importance of a cure, while 11 described the need to reduce the number of times they took the pill from daily to maybe weekly or monthly. There were suggestions by the same eight interviewees that they used non-prescribed herbal medicines without withdrawing from ART in the hope that they could one day be cured. Take for instance Mutukwa's story below about how he would remain on ART as long as there was no cure:

The only thing I find challenging is the fact that I have to take my drugs for the rest of my life. And the fact that there is no cure for HIV. [...] It was difficult for me to accept. I could not imagine myself or to the hospital for treatment and take medicine every day.

The taking of ARVs every day was far from being easy, and was more of a challenge than the worry of having a virus. Besides a cure, informants talked about improved dosage from taking the pill on a daily basis to maybe once in three months. For several participants, the absence of a cure could at least be mitigated by having drugs to be taken periodically rather than daily. It was reported that taking pills daily without any alternative was a burden. In this regard, consider Nandi, who said:

Nandi (Woman, 54): Taking medicine is not an easy thing. If it was injectable I think it would be better for

me. If we could be injected for a year, like it is done for family planning, and then go for the other year. Taking pills every single day is not easy. Sometimes I forget, especially when I'm out of my home. I should take medicine at 18:00 hours. It's already 18:00 hours and I am still here at work. So taking drugs every day is not easy, one needs to be disciplined. Wherever you go, you need to have the medicine in the bag. It is more like a demon we are worshipping.

Surveillance by medical practitioners was associated with some uncertainties around ART's workings. Twenty-two participants indicated that their primary concern was around two key but separate issues: treatment failure, and cuts in the supply of free drugs in the future owing to potential changes in policy.

Emonda (Woman, 35): Only hope the government would not stop giving ARV drugs for free. I can imagine that if the drugs were not free, many will perish. To only depend on diet cannot work. [...] My worry is that should the government stop subsidising the ARVs our country's production levels will fall down. Almost every year we will be losing millions of teachers. I hope even the donors helping with supplying ART should continue, because without them we are doomed.

Interviewees reported uncertainties and worry when the media reported drug shortages at clinics. However, the majority of participants appreciated the government's role in the supply of drugs; all agreed that they were worried about the future supply of ART. Talking about this issue, Kalaluka said: Kalaluka (Man, 49): When I hear on television that there is a short supply of the drugs I get sick

When I hear on television that there is a short supply of the drugs I get sick psychologically. When I go for review and I am given for a month or two weeks, I get worried. Sometimes we hear rumours that the government will stop supplying the drugs. We get worried because we are surviving because of these drugs. When I stop taking Septrin, I get affected, what more when I stop taking ARVs because they are no longer being given.

The quote above reflects mental distress among participants, especially during drug rationing. Fears about buying the pills out of their income were a concern for many interviewees, as they noted that their current salaries could not cover all HIV treatment services in the absence of free access to treatment. Because most of them said they were unable to even afford nutritious food, paying for ARVs could be hard if not impossible. In the same vein, it was suggested that taking a pill on daily basis acted like a reminder that something was wrong with their bodies or that they were ill. One interviewee even described the treatment as enslaving due to the strict timetable for taking the drug:

Ngolwa (Man, 52):

What binds me only is that I have to make sure that I have eaten before taking the medication. The timetable as well. There was some news where somebody was talking about the future medication where somebody will be given an injection maybe for a month. That can give us a lot of freedom. The only thing that enslaves us is at 20:30 hours I have to take the medicine.

The description above shows some frustration at what could be called 'pharmaceutical colonialism'. In connection to discussions around better dosage regimens, half of the interviewees talked about their fear of death. Fifteen (37%) interviewees said that they and their families always worried about dying due to HIV in spite of being on ART. Responses from about 50% of the participants showed that perceptions of ART's lesser effectiveness drew from reports and stories of people who were living with HIV dying whilst on treatment. Perhaps this result reflected the limited medical understandings and substantiation of ART's functioning in the social element of information-sharing.

Together these results provide some insight into the contradiction between interviewees' knowledge of the workings of the medicine they were taking and its relation to death. It was apparent that one could die of HIV only if one did not adhere to ART and did not follow healthy a lifestyle. But fear of ART's failure in bodies was mentioned in relation to the need for a cure or reduced dosage by 60% of participants. Thus, the worry about taking drugs for life, without any hope for any non-daily curative drugs, caused mental health issues.

# Discussion

Drawing from the qualitative accounts of ART experiences I show how therapeutic citizenship is highly gendered. Our findings show higher negativity for women, with the majority reporting internalised stigma, and men reporting more medical challenges, as shown by Amin (2015), Camlin (2017), Colvin (2019), Petersen et al. (2017) and Russell (2019). This study found that about 50% of all the women had sought treatment based on external triggers such as the death of a spouse, whilst 70% of the sampled men had waited until they were sick to be tested and commence ART, as research elsewhere (Fleming et al., 2016; Colvin, 2019; UNAIDS, 2016; Whyte, 2015) has shown. HIV literature on Zambia does not explicitly compare man and woman ART adherence. Comparative methods in the study of illness and health appear limited but common in the field politics (Mulubale, 2018). However, survey statistics based on regions, as demonstrated by UNAIDS (2017) and Whiteside (2016:8–9), often

do not capture why men are mostly not willing to test until they are sick, as found in Barnett and Blaikie's (1992) study. This study found that most men did not seek medical help early due to a perceived lack of privacy and patriarchal cultural tendencies of wanting to seem strong at all times. The study also confirms previous studies on women being longer-term HIV survivors due to earlier testing and treatment (Campbell et al., 2012; Hegdahl et al., 2016; Murray et al., 2013; Whyte, 2015).

Generational differences in ART experiences are a key finding in this research. This study found that age and period of HIV diagnosis determined how participants lived on ART, as also found by Mulubale (2020). Generational differences include for example that people who are diagnosed more recently and/or get treatment directly after diagnosis do better. There is more on generational differences in global North HIV research, such as Franklin et al. (2019). This is a new finding in global South contexts, partly because 'universal' ART access and access directly after treatment is much newer in those contexts, and in studies that focus on generational differences in terms of risk of HIV transmission, such as Street et al. (2016).

Despite the above, long-term issues around HIV were mainly psychosocial, and the short-term ones were more about the negative bodily effects of being on ART, as found by Nixon (2017). It was the positive impact that ART had on the body that was seen as a positive consequence of adherence over time. In the literature, no empirical work exists that clearly contrasts ART's long-term and short-term impacts on HIV positive teachers in Zambia. However, other groups elsewhere report successfully conducting their day-to-day duties through ART, which enables functional health long term, as described by Larsen (2016). This research found nevertheless that over 50% of participants did not find the notion of taking pills every day and long term 'normal', indicating the complexities of long-term adjustments to living with HIV and ART. The sustainability of the ART drug supply from the government was of concern and a source of anxiety for 22 participants. Perceived HIV treatment failures created uncertainties around ART, focused on claims of its damage to the liver, as Nixon (2017) found – a perhaps surprising finding about the persistence of this concern, given the much-improved effects of ART.

However, the reported recovery of physical health and social interaction improvements through ART continued to provide a sense of therapeutic hope among 27 participants. These findings seem to be consistent with other research which found that men on ART were pleased with their physical health as they were now able to work and take care of themselves and their families, and women similarly, with the addition that they were also hopeful of a cure because they could conduct household tasks, which gave them a sense of normalcy. Medical records and hospital checks on adherence are forms of surveillance systems which connect different spaces, periods and effects of ART on bodies. They were reported in ambiguous terms, as normalisation, and as a contradicting characterisation of the everyday aspects of living with HIV that produce an ART atmosphere, as also found by Ellis et al. (2013) in their study on affective atmospheres of surveillance.

The results here also show that when one is facing a life-threatening health condition, earlier aspirations as well as relationships become weakened, even when that condition becomes chronic and liveable. This happens through self-withdrawal from existing social networks, even when participants are doing well, as has been shown by Campbell et al. (2005) and Goffman (1963).

ART's workings in the findings relate to enabling participants to teach and carry out other duties after recovery. The significance of therapeutic citizenship for the profession and for being good citizens is also embedded in positive teachers' abilities to relate well among themselves rather than with negative teachers – that is, if they know or are open about their status. Results suggests that being a good citizen is about adherence to ART and learning from the negative consequences of defaulting on 'taking medicine' – a feature of HIV citizenship.

One of the therapeutic citizenship aspects found by this research is informal networks, a feature of many kinds of citizenship, that seem to sustain HIV therapeutic citizenship among this participant group. It is clear in the results that participants used their diagnosis to associate with peers, and they spent time with each other as well as making visits to the homes of their colleagues, especially those housed within the school premises. This was noted with a group of three-women teachers (all participants) advising another HIV positive colleague, who was not feeling well, on best health practices. However, positive teachers in some cases seemed isolated, shy and uninterested in any form of general discussion, even on non-health related topics, with colleagues in school staffrooms. Also, some HIV positive man teachers used the phrase 'Club Z' to refer to being on ART – a name borrowed from a local telecom company; this implied a 'top-up' with reference to airtime (credit), but its actual usage by these teachers was 'topping up on life' (prolonging life) through ART drugs. While this phrase could name a positive social association between people, it also could be said implicitly reduce life and citizenship with HIV to a marginal extra. The above findings describe forms of HIV socialities that enhanced a sense of shared critical HIV citizenship, as shown not only by elements of self-care but also by teachers being caregivers to their HIV positive learners, as also shown by Campbell et al. (2016) and Persson (2016). Nonetheless, the above go beyond Campbell et al. and Persson's studies, by showing the 'muddled' position that teachers find themselves when living with HIV and supposed to be careers and supportive to learners who also on ART like them.

ART is not just about control of HIV, but is also part of the social and political infrastructure for good citizenship in a high prevalence country such as Zambia. HIV/AIDS activism and power-brokering activities are

present at local and international levels (Mbali, 2016; Mulubale, Squire and Rohleder, 2020). There are national movements that appear to have created both active and passive citizens through HIV representations. Based on the results, the HIV treatment process is reducing differentials are reducing, but the HIV status for those who are positive does not change. For example, those with more relative views about the pandemic, and perhaps individual under-recognised problems with HIV's medicalisation and normalisation, are struggling for membership between the two groups. The results seem to say, that some people become included within therapeutic citizenship – despite its difficulties or 'muddle' – and that some are in a sense 'immune' to it and not part of it, probably based on their own individual medical/stigma difficulties with ART.

The political nature of therapeutic citizenship is shown in the state-citizen contract and the roles of NGOs in HIV. The role of government in HIV treatment services is sometimes undercut by the work of NGOs. The state does not provide services beyond the supply of ART, yet NGOs continue to mediate within an informal economy of psychosocial resources for living with HIV, similar to findings by Russel et al. (2015). Consequently, claims and entitlements to 'biological citizenship' beyond medication are limited to humanitarian social welfare, without any legal criteria that recognise the status and privileges of being a therapeutic citizen in a social as well as a medical sense, as also shown by Rose and Novas (2005) as well as Young et al. (2019). The role of NGOs through community health workers was found to cultivate supportive conditions for people living with HIV, away from the hostile environment of the workplace, at hospital as well as home.

From the above, other concepts, such as socio-political capital, emerge as an extended framing of therapeutic citizenship. The notion of socio-political capital is useful, as it is central to mainstream development discourses. Insofar as teachers in Zambia have some level of ability to influence the public status quo, they enjoy socio-political capital. For those living on ART, socio-political capital is noticed in the sharing of material resources based on professional and social networks (Fine, 2003; Kagee et al., 2014).

# Conclusion

How HIV citizenship is understood is also, the study's findings suggest, highly gendered. The results show glaring differences in knowledge and coping strategies between man and woman participants. For example, it has been noted here that ART was mainly reported as working for women, whereas for men it was restricting. The repetition of HIV difficulties in responses was more common among men. Hence, ART chronicity was presented in a positive way by more women than men in the sample. Generational differences played a role in HIV chronicity, and in how identities were produced. The longer they had lived on ART, the more participants had integrated other parts of their lives into a medicalised lifestyle, while also being able to differentiate the parts of their lives that were not related to HIV - identity were not defined only by the condition. As a common finding, participants who said HIV did not define them did not belong to the earlier generations - independently of their time on ART - who had been part of the HIV/AIDS 'crisis', as described in Barnett and Blaikie (1992). But as discussed above, HIV is no longer a crisis in Zambia, and the 'HIV does not define me' narrative had less emphasis than it might have done earlier in the pandemic. Therefore, I have established through this study that to some extent in Zambia and elsewhere in Africa, HIV citizenship becomes a larger thing that assumes a defining role in 'non-HIV' aspects of people's lives but does not reduce them to it - something that this research has added, since other studies, such as Whyte (2014) and Bernays et al. (2016), seem narrow as they do not focus on HIV research elements' related factors that this research has taken forward.

# References

- Amin, A. (2015). Addressing gender inequalities to improve the sexual and reproductive health and wellbeing of women living with HIV. *Journal of the International AIDS Society*, 18(Suppl 5):20302 Available at: http://www.jiasociety.org/index.php/jias/article/view/20302
- Barnett, T. and Blaikie, P. (1992). AIDS in Africa: Its Present and Future Impact. Chichester: John Wiley and Sons.
- Bernays, S., S. Paparini, D. Gibb and J. Seeley (2016). When information does not suffice: young people living with HIV and communication about ART adherence in the clinic, *Vulnerable Children and Youth Studies*, 11:1, 60-68, DOI: 10.1080/17450128.2015.1128581
- Braun V. and Clarke V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. The Psychologist, 26 (2). Pp 120-123. ISSN 0952-8229. Available at: http://eprints.uwe.ac.uk/21155
- Braun V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2): 77-101.
- Bulley, B.S (2014). Governmentality: Notes on the Thoughts of Michel Foucault. *Key Concept Series* Critical Legal Thinking online platform. Available at: http://criticallegalthinking.com/2014/12/02/governmentality-notes-thought-michel-foucault/
- Camlin, C.S (2017). Redemption of the "spoiled identity:" the role of HIV-positive individuals in HIV care cascade

interventions. Journal of the International AIDS Society. https://doi.org/10.1002/jia2.25023 Accessed on: 14/02/2019

- Campbell C, et al (2016). Can Schools Support HIV/AIDS-Affected Children? Exploring the 'Ethic of Care' amongst Rural Zimbabwean Teachers. PLoS ONE 11(1): e0146322. Available at: https://doi.org/10.1371/journal.pone.0146322
- Campbell, C. et al. (2005). The impact of social environments on the effectiveness of youth HIV prevention: A South African case study. *AIDS Care* 17 (4): 471-8
- Campbell, C. et al. (2012). Social capital and HIV competent communities: The role of community groups in managing HIV/AIDS in rural Zimbabwe. *AIDS Care 25*, Special Supplement: S114-22. Available: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3701935/
- Colvin. C.J (2019). Strategies for engaging men in HIV services. The Lancet HIV.
- Ellis, D., Tucker, I., and Harper, D. (2013). The affective atmospheres of surveillance. *Theory & Psychology*, 23(6), 716-731.
- Fine, B. (2003). Social capital: The World Bank's fungible friend. Journal of Agrarian Change, 3(4), 586-603.
- Fleming, P.J et al. (2016) What role can gender-transformative programming for men play in increasing men's HIV testing and engagement in HIV care and treatment in South Africa?, *Culture, Health & Sexuality*, *18*:11, 1251-1264, DOI: 10.1080/13691058.2016.1183045
- Foucault, M. (2008). The Birth of Bio-politics. Lectures at the Collège de France 1978–1979. In M. Snellart, F. Ewald, A. Fontana, and A. I. Davidson. (ed) Translation by G. Burchell. Basingstoke: Palgrave.
- Franklin, J., Gruschow, S., Joslin, I., et al. (2019). 208. Intergenerational Relationships and Generational Differences In Access To Health-Related Resources Among Young Transwomen: A Qualitative Analysis. *Journal of Adolescent Health, 64*(2), S106.
- Goffman. E (1963). Stigma: Notes on the Management of Spoiled Identity. New Jersey: Penguin Books.
- Hegdahl, H.K, Fylkesnes, K.M, and Sandøy, I.F (2016). Sex Differences in HIV Prevalence Persist over Time: Evidence from 18 Countries in sub- Saharan Africa. *PLoS ONE 11*(2): e0148502. doi:10.1371/journal.pone.0148502
- Kagee, A., Swartz, A., and Swartz, L. (2014). Theorising beyond the individual: Adherence to antiretroviral therapy in resource-constrained societies. Journal of Health Psychology, 19(1), 103-9.
- Kelly, M.J. (2000). What HIV/AIDS Can Do to Education, and What Education Can Do to HIV/AIDS. Lusaka: UNZA.
- Larsen, P.D (2016). 'Chronicity' in Lubkin's Chronic Ilness: Impact and Intervention, 9th Edition. Washington DC: Jones & Bartlett Learning.
- Lock, M and Nguyen K.V (2018). An Anthropology of Biomedicine. Second Edition. Wiley-Blackwell.
- Marsland R. (2012). (Bio)sociality and HIV in Tanzania: finding a living to support a life. *Medical Anthropology Quarterly*, *26*(4), 470-85.
- Mattes, D. (2011). "We are just supposed to be quiet": The production of adherence to antiretroviral treatment in urban Tanzania. Medical anthropology, 30(2), 158-182.
- Mbali, M. (2016). AIDS Activism and the State in Post-Apartheid South Africa at Twenty. South Africa after Apartheid: Policies and Challenges of the Democratic Transition, 49.
- McDonald K., et al. (2016). Chronic Disease Self Management by People with HIV. *Qualitative Health Research*. Vol 26 (6) 863 870. DOI: 10.1177/1049732315600415
- Mulubale, S., Rohleder, P., & Squire, C. (2020). LOLS@ stigma: comedy as activism in the changing times of the HIV epidemic. *Critical Public Health*, 1-13.
- Mulubale, S. (2019). Researching Politics in Africa: Reflections on Comparative Design Using Written Materials in Understanding Identity Politics Within the Context of African Societies. SAGE Publications Ltd. DOI: http://dx.doi.org/10.4135/9781526488060
- Mulubale, S. (2020). Understanding the Seriousness of 'Self' Identity and Changing Process of HIV among Zambian School Teachers Living with Antiretroviral Therapy (ART). *Athens Journal of Health and Medical Sciences*, Volume 7: Issue 4 pp 197 216. DOI= 10.30958/ajhms.7-4-2.
- Murray, C.J.L et al. (2013). Global, regional, and national incidence and mortality for HIV, tuberculosis, and malaria during 1990–2013: a systematic analysis for the Global Burden of Disease Study. *The Lancet*. 384(9947):1005–70.
- Nguyen, K. V (2010). The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS. Durham, NC: Duke University Press.
- Nixon, S.A (2017). Optimism alongside new challenges: using a rehabilitation framework to explore experiences of a qualitative longitudinal cohort of people living with HIV on antiretroviral treatment in Lusaka, Zambia.
- Paparini, S. and Rhodes, T. (2016). The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy, *Critical Public Health Journal*. Vol 26: 5 pp 501 – 517.

- Patterson A.S. (2015). Engaging Therapeutic Citizenship and Clientship: Untangling the reasons for therapeutic pacifism among people living with HIV in urban Zambia, Global Public Health. International Journal for Research, Policy and Practice. DOI:10.1080/17441692.2015.1070053
- Persson, A. (2016). 'The world has changed': pharmaceutical citizenship and the reimagining of serodiscordant sexuality among couples with mixed HIV status in Australia. Sociology of Health & Illness Vol. 38 No. 3, pp. 380–395 doi: 10.1111/1467-9566.12347
- Persson, A., and Newman, C. (2006). Potency and vulnerability: Troubled 'selves' in the context of antiretroviral therapy. *Social Science & Medicine*, *63*(6): 1586-1596.
- Petryna, A. (2004). Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations. In Available at: http://www.jstor.org/stable/3655243?seq=1&cid=pdf-reference#refces\_tab\_contents Accessed on: 22/02/2019
- Rooks-Peck, et al. (2018). Mental health and retention in HIV care: A systematic review and meta-analysis. *Health Psychology*, *37*(6), 574-585. http://dx.doi.org/10.1037/hea0000606 Accessed on 10/07/2019
- Rose, N. and Novas C. (2005). Biological Citizens, In Ong, A. and S. J. Collier (eds.) *Global assemblages: technology, politics, and ethics as anthropological problems.* Oxford, Blackwell Publishing. pp 439 464.
- Russell, S. (2019). Men's Refashioning of Masculine Identities in Uganda and Their Self-Management of HIV Treatment. *Qualitative Health Research* 2.
- Squire, C. (2013). Living with HIV and ARVs: Three Letter Lives. UK, Palgrave Macmillan.
- Steenbergen, B. (1994). The Condition of Citizenship. London: Sage
- Street, R. A., Reddy, T., and Ramjee, G. (2016). The generational effect on age disparate partnerships and the risk for human immunodeficiency virus and sexually transmitted infections acquisition. *International journal of STD & AIDS*, 27(9), 746-752.
- UNAIDS (2015). 'UNAIDS announces that the goal of 15 million people on life-saving HIV treatment by 2015 has been met nine months ahead of schedule.'
- UNAIDS (2016). Get on the Fast Track: The life cycle approach to HIV, finding solutions for everyone at every stage of life. Available at: http://www.unaids.org/sites/default/files/media\_asset/Get-on-the-Fast-Track en.pdf Accessed 14/02/2019
- Ware, N. C., et al. (2009). Explaining adherence success in sub-Saharan Africa: an ethnographic study. *PLoS Med* 6(1), e1000011. doi: 10.1371/journal.pmed.1000011
- Whiteside, A. (2016). HIV and AIDS: a very short introduction. Oxford: Oxford University Press.
- Whyte, S.R. (2013). Chronicity and control: framing 'noncommunicable diseases' in Africa, Anthropology & Medicine, 19:1, 63-74
- Whyte, S.R. (2015). Working and Surviving: Government Employees on ART in Uganda. In W Geissler (ed.), Para-States and Medical Science: Making African Global Health. Durham and London: Duke University Press. pp 207-233.
- Whyte, S.R. (ed) (2014). Second Chances: Surviving AIDS in Uganda. Durham: Duke University Press.
- Whyte, S.R., Whyte, M.A., Meinert, L., and Twebaze, J. (2013). Therapeutic clientship: Belonging in Uganda's projectified landscape of AIDS Care. In J. Biehl, & A. Petryna (Eds.) *When people come first: Critical studies in global health*. Princeton: Princeton University Press.
- Young, I., Davis, M., Flowers, P., and McDaid, L. M. (2019). Navigating HIV citizenship: identities, risks and biological citizenship in the treatment as prevention era. *Health, Risk & Society*, 21(1-2), 1-16.