

`Treatment is not yet necessary': delays in seeking access to HIV-treatment in Uganda and Zimbabwe

Rachel Kawuma¹, Janet Seeley^{1,2*}, Zivai Mupambireyi³, Frances Cowan⁴, Sarah Bernays⁵ and the REALITY Trial Team

1. MRC/UVRI Uganda Research Unit on AIDS, Entebbe Uganda and
2. Global Health and Development Department, London School of Hygiene and Tropical Medicine, London UK
3. Centre for Sexual Health and HIV/AIDS Research, Harare, Zimbabwe
4. International Public Health Department, Liverpool of Tropical Medicine, Liverpool, UK and Centre for Sexual Health and HIV/AIDS Research, Harare, Zimbabwe
5. School of Public Health, University of Sydney, Sydney, Australia

*Corresponding author: Janet Seeley, London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, London, WC1H 9SH, UK. tel. +44 207 958 8268 (janet.seeley@lshtm.ac.uk)

ACKNOWLEDGEMENTS

This work was supported by the Joint Global Health Trials Scheme of the Medical Research Council (MRC), the UK Department for International Development and the Wellcome Trust through a grant (G1100693), with additional support from the PENTA Foundation. We thank the participants and staff members in the centres that participated in the trial. We are grateful to Alex Szubert for his support and Prof Di Gibb, Prof Sarah Walker, Prof Frank Post, Prof Sir Ian Weller, Anna Griffiths and Dr Sarah Pett for comments on this manuscript.

Ethical considerations

The study protocol was reviewed and approved by the Research Ethics Committee at the Joint Clinical Research Council (JCRC) and the National Council for Science and Technology (UNCST) in Uganda. In Zimbabwe the study was granted ethical approval by the Joint Parirenyatwa Hospital and College of Health Sciences Research Ethics Committee (JREC) and the Medical Research Council of Zimbabwe (MRCZ/A/1700). Written consent and assent was obtained from all the participants; parental consent was sought for all children below 18 years.

`Treatment is not yet necessary': delays in seeking access to HIV-treatment in Uganda and Zimbabwe

Abstract

We examine the logic that individuals use to account for the delay to go for an HIV test and/or to initiate HIV treatment. Our qualitative study, situated within the REALITY trial (Reduction of Early Mortality in HIV infected adults and children starting antiretroviral), was conducted in Uganda and Zimbabwe in 2015. Forty-eight participants (different age groups, sex, viral load/WHO disease stage) were included. Each participant had two interviews (one after 4 weeks of participation in the trial the other after 12 weeks). If a person could manage presenting symptoms, they felt they had “more time” before starting ART. Their reluctance to have an HIV test (despite deteriorating health) arose from a belief that they were not `sick`, that treatment was `not yet necessary`. People in our study did not consider themselves as presenting `late`, and treatment was not considered urgent as long as they considered their health to be `good enough`.

KEYWORDS: HIV; antiretroviral therapy; Universal Test and Treat; treatment delays; Uganda; Zimbabwe; Africa

Introduction

By the end of 2016 it was estimated that 19.5 million of the 36.7 million people living with HIV globally were accessing anti-retroviral therapy (ART) (UNAIDS, 2017). Despite the enormity of progress in providing access to treatment, receiving a positive HIV-test result and being encouraged to start ART as soon as possible may still present a significant challenge.

Access to HIV treatment sustains health, but for someone who may not feel ill or question an HIV-positive test result 'their perceptions of their life-worlds' may not include any acknowledgement that they need any form of treatment (Takahashi, Wiebe, & Rodriguez, 2001, p. 847). There is a fine line between sickness and health: being healthy may be an ability to adapt and self-manage (Huber et al., 2011). For some people living with HIV who may not have been tested, or for those who have been tested but choose not to start treatment, this self-management continues while any form of ill-health can be contained. Starting ART is an acceptance that for adaptation and self-management to continue, the time has come for external support (Russell et al, 2016) and health can only be sustained by taking treatment.

Wilton (1996) noted in his ethnography among nine symptomatic HIV-positive men (from a high-income setting) not yet on ART, that the efforts involved in incorporating the changing material and perceived parameters of daily life with HIV, required a considerable realignment of individuals' 'life worlds'. Although encompassing different routines and threats, this remains true for those now living with HIV on ART, given their perceived fragility of health and the time investment required to engage in long term clinical care to maintain their health (Winchester et al.,

2017). Much has been written about the current manageability of an HIV diagnosis, however reconciling oneself to the altered realities of living with HIV, even within the sustained health offered by ART, may still take time (Mutabazi-Mwesigire, Seeley, Martin, & Katamba, 2014; Russell & Seeley, 2010). Reconciling the health-illness tension into self-identity (Takahashi et al., 2001) may be compounded by the risk of being identified by others as ‘ill/ HIV-positive’ if seen to be attending a clinic. This fear can be particularly prominent when there is no other health explanation that they could plausibly give for their utilization of medical services (Treves-Kagan et al., 2016).

Time and timeliness are pivotal factors in whether the current HIV prevention and treatment agendas of ‘test and treat’ (immediate treatment on diagnosis) and ‘treatment as prevention’ (reduced viral load as a result of taking treatment, thus reducing infectivity) will be successful (Dieffenbach & Fauci, 2009; WHO, 2012, 2016). The concept of ‘timeliness’ is framed through a biomedical lens and operates on the assumption that there is a shared understanding between patient and clinician about how time is experienced, measured and consumed. It is relatively rare to consider a more emic perspective on what might constitute an individual’s criteria for when the ‘right time’ to initiate treatment is and what might underpin their definition of timeliness.

In general, the exploration of time as a critical dimension in shaping health-seeking behaviour and the ways in which it shapes health has been relatively neglected (Strazdins et al., 2011). Notable exceptions to this are the body of chronic illness research which has focused on time as a resource for accessing care and the competing priorities and commitments which impede the time a person

may have to seek treatment (Dempsey, Dracup, & Moser, 1995; Schoenberg, Peters, & Drew, 2003). Although increasing attention is paid to refusals (Katz & Bangsberg, 2016; Katz et al., 2015) and ‘lateness’ in relation to ART (see, for example, Kigozi et al., 2009; Mocroft et al., 2013; Moreno, Mocroft, & Monforte, 2010; Mukolo, Villegas, Aliyu, & Wallston, 2013; Parrott et al., 2011), given the role time plays in the successful execution of the broad HIV prevention and treatment agenda, understanding what ‘late’ might mean for an individual has not received so much attention. Clinically there is variation in how quickly some individuals need to get onto ART having been infected, with some people with an infection that progresses slowly effectively having ‘more time’ to initiate treatment. However the clinical messaging, which now focuses on getting everyone onto ART as soon as possible, can not necessarily engage with the nuances of this variation. It is important to pay attention to the divergence between this global clinical policy and how the urgency and necessity of starting treatment is interpreted by those that this policy aims to reach.

An irony of the success of ART is that it can render HIV, and thus its own necessity, invisible. What is still visible are some of the physical scarring and side-effects associated with earlier ART options. The effects of lipodystrophy (the redistribution of body fat) caused by some earlier drug regimens (Staszewski et al., 1999) may continue to embody to some within the community the risky consequences, both physical and social, of being treated for HIV (Katz et al., 2015).

Therefore, the concealment of the daily success of ART treatment for those who initiated treatment before becoming symptomatic, may mean that there is a time lag between the newer realities of

life on ART and the outdated but still prevailing social norms about the compromised health and social status of those on ART. Seen through this lens, rather than that of the clinical evidence, if their untreated HIV remains personally manageable, the incentives for early treatment to maintain relative health may be less compelling. An ambiguity may still exist for them in whether immediate ART is the route to healthiness (Curran et al., 2014).

With the advent of 'test and treat', a person 'delays' treatment if they do not start ART soon after their HIV-positive diagnosis being confirmed. There has been a rapid change in policy about when is the 'right time' to initiate HIV treatment (Insight Start Study Group, 2015), and the subsequent incentives for 'timely' presentation for diagnosis and treatment. Is this information being incorporated into the decisions and actions about treatment and provoking a recalibration of an individual's expectations of what their life might be to live with HIV through being on ART (Russell et al., 2016; Sprangers & Schwartz, 1999)? In this paper, we examine the logic that individuals who presented very late for treatment ($CD4 < 100$ cells/mm³) use to account for the time they took to go for an HIV test and/ or to initiate HIV treatment.

The REALITY trial (Reduction of EArly mortaLITY in HIV-infected adults and children starting antiretroviral therapy) was conducted in nine centres in four countries (Kenya, Malawi, Uganda and Zimbabwe). This was a randomized controlled trial with the primary objective of identifying effective, safe and acceptable interventions to reduce early mortality in HIV-positive adults, adolescents, and older children (five years or more) initiating anti-retroviral therapy (ART) with $CD4 < 100$ cells/mm³. Three methods were used to reduce early mortality following ART initiation:

(i) increasing the potency of ART with a 12 week induction period; (ii) augmented prophylaxis against opportunistic/bacterial infections and helminths for 12 weeks and (iii) ready-to-use supplementary food for 12 weeks. Each intervention was compared with standard of care (Hakim et al., 2017).

In response to addressing the trial research question about reducing early mortality among those initiating ART, a qualitative sub-study was undertaken to find out the reasons why participants presented late for HIV treatment. This sub-study was conducted at two sites in Uganda: Gulu (northern Uganda) and Mbarara (south western Uganda), and the site in Harare, Zimbabwe.

Methods

Study Population and Sampling

Forty-eight participants enrolled in the REALITY Trial participated in the qualitative sub study in 2015. Males and females aged 10 years and above were recruited, 24 from Uganda and 24 from Zimbabwe. Purposive sampling was used to include participants randomized from the two extreme arms in the trial; half on the intervention arm which combined all three interventions being investigated namely, participants receiving both enhanced ART and anti-infection treatment plus ready to use food supplements for 12 weeks and the other half receiving none of the interventions where participants received standard of care. The qualitative sample was designed to be as representative as possible of the various age groups and gender of the trial population.

The REALITY social science study was conducted in research settings in Mbarara and Gulu, two of the four REALITY trial sites in Uganda. The Mbarara site is located within a research facility in the regional referral hospital where there is a department which handles HIV testing and

treatment which receives many patients from within Mbarara and neighbouring districts. The Gulu site was based in a specialist research clinic which provides for patients from Gulu and neighbouring districts.

In Zimbabwe the REALITY trial site was in Harare, in a centre set up for clinical research situated within a referral hospital. Participants came from Harare and the surrounding areas.

Data collection and Analysis

Two interviews were conducted with each participant; phase 1 interviews were conducted after the participants had been in the trial for four weeks to learn about their life before ART and how they came to join the REALITY trial. Phase 2 interviews were conducted after the 12 week intervention had concluded to find out about the adjustment processes that followed being initiated on ART.

Topics that were discussed included adherence, disclosure and social support systems that were available to the participants once they started HIV treatment. Participants were asked about their illness history and what prompted them to take an HIV test, to understand what factors may have influenced the decision to test for HIV and what steps they took after the HIV test to seek treatment and care. Although all trial participants were initiated onto ART when enrolled into the trial, some participants who tested positive at the start of the trial may have received a positive test result at an earlier point, but not initiated treatment. For those participants who had had prior confirmation of their HIV-positive status we asked them why they had not sought treatment soon after receiving a positive test result.

All the interviews were audio recorded, transcribed verbatim and translated from local languages into English. A grounded analytic approach to thematic analysis was adopted, using systematic case comparison, including across study sites and key sampling dimensions such as gender and age, and negative case analysis throughout (Strauss & Corbin, 1994). Core themes which emerged through our first level (participant description) and second level (concept-driven categories) coding included: good enough health; consumption of time; curtailed 'choices; and community discourses about anti-retroviral treatment.

Findings

Table 1 below shows details of participants by age and sex as well as WHO Stage at presentation (see supplementary material for Table 2 including viral load and CD4 count data). We have used WHO stage in this table, because how ill someone felt was a very important factor in whether a person presented for testing. Those presenting with Stage 4 symptoms were often very ill indeed.

Table 1. Study participant country, age, sex, Marital status, HIV status before REALITY trial and WHO disease stage on first visit to study clinic

Country	Age	Sex	Marital Status	Aware of HIV status 3 months before REALITY trial	WHO Stage*
Uganda	39	F	Single	Yes	1
Uganda	30	M	Single	Yes	1
Uganda	32	F	Single	Yes	1
Uganda	38	F	Married	No	1
Zimbabwe	31	M	Married	No	1
Uganda	36	F	Married	Yes	1
Uganda	36	M	Married	No	1
Uganda	38	F	Single	Yes	1
Uganda	50	M	Married	Yes	1
Uganda	40	M	Married	No	1
Zimbabwe	40	M	Married	No	1
Uganda	24	F	Married	Yes	1
Uganda	47	M	Single	No	1
Uganda	30	F	Single	Yes	1
Uganda	50	F	Single	Yes	1
Zimbabwe	12	M	Single	Yes	2
Zimbabwe	46	M	Married	Yes	2
Uganda	30	M	Single	Yes	2
Uganda	32	F	Single	No	2

Zimbabwe	17	M	Single	No	2
Zimbabwe	33	F	Single	No	2
Uganda	30	F	Single	Yes	2
Zimbabwe	38	F	Divorced	Yes	2
Uganda	26	M	Married	Yes	2
Zimbabwe	29	M	Single	No	2
Zimbabwe	53	F	Divorced	Yes	3
Zimbabwe	42	M	Married	No	3
Zimbabwe	33	M	Widowed	Yes	3
Zimbabwe	12	F	Single	Yes	3
Zimbabwe	40	M	Married	Yes	3
Zimbabwe	57	F	Married	Yes	3
Uganda	39	M	Married	Yes	3
Zimbabwe	32	F	Divorced	Yes	3
Uganda	63	M	Married	Yes	3
Zimbabwe	35	F	Widowed	No	3
Zimbabwe	44	M	Divorced	No	3
Zimbabwe	29	M	Married	Yes	3
Zimbabwe	43	M	Divorced	No	3
Uganda	52	M	Married	Yes	3
Zimbabwe	53	F	Widowed	No	3
Zimbabwe	46	F	Married	No	4
Zimbabwe	51	M	Married	No	4
Zimbabwe	47	F	Divorced	Yes	4
Uganda	38	M	Single	No	4
Uganda	28	M	Single	No	4
Zimbabwe	32	F	Divorced	Yes	4
Uganda	23	F	Single	Yes	4
Uganda	19	M	Single	No	4

* See <http://www.who.int/hiv/pub/guidelines/HIVstaging150307.pdf> for an explanation of the staging

'Late' presentation:

By definition, all participants in the trial had low CD4 cell counts (<100 cells/mm³), but a substantial number were very low (<50 or even <10 cells/mm³). Viral loads were also very high (Table 2). However, these laboratory test results were not known to participants. In contrast, several participants presented for HIV testing with many symptoms. The deterioration of their health tended to have been gradual, which meant that they were able to ignore or minimise the significance of their worsening condition. Accounting for why they presented late for HIV testing, many stated that they thought that their illness was just 'ordinary' and or 'minor ailment' which would resolve by itself or with self-medication.

I would mainly feel weak and buy tablets to gain energy and sometimes I would fail to eat food (no appetite). I was a very fat woman weighing 90kgs but then I noticed I was losing weight and all my clothes would fall off so I always wondered what might be the problem...just losing weight, itching all over and I would just think that maybe it is an illness probably Candida so I would buy tablets and insert there (vagina). I was suspecting diseases such as syphilis and not HIV. (Female, 50 years, Uganda).

An intrinsic thread within many participants' accounts was an expectation that it was not uncommon for their health to be compromised to varying extents at different points. Some adverse physical symptoms were to be anticipated and if they were manageable then this did not disrupt their sense of 'healthiness'. Health was thus defined as an absence of a debilitating physical

condition, rather than as a fulfilment of an ideal physical state. Two men, both WHO stage 3, demonstrated this when they said:

It never came into my mind [that it was HIV-related] [...] it's common for one to get sick here and there then you get well and get back to your daily life, you start doing what you were doing or just doing your work. (Male, 43 years, Zimbabwe)

So, these are the kind of things [illness] you expect as a living being. Trees do lose their leaves at some point and so you may think that it is just something people experience and it will what? It will come to pass. That is the "belief" I had, that it's nothing serious and that it is a phase which will eventually go away on its own. (Male, 42 years, Zimbabwe).

In the face of evident ill-health and in a society where there is a relatively high risk of acquiring HIV, participants reporting having considered their health problems at the time to still be manageable. For as long as it was feasible, they had treated the presenting symptoms at general clinics or through using herbal treatment. For instance, a 38 year old man in Uganda (WHO stage 4), said:

I used to be sick and would feel so weak but was using herbal medicine. I had a skin rash and lots of blisters so I would self-medicate...knowing that it was syphilis, I went to the hospital and they also tested it and treated syphilis.

A 36 year old man (WHO Stage 1), also from Uganda, commented:

I would get treatment for malaria and cough but they wouldn't cure fast; they get cured for one month and recur again. I was buying it (treatment) in small towns where there are clinics with drugs. But I noticed that my energy was becoming low.

Not late, instead not yet necessary:

Prior to getting to the point of testing and getting treatment, most of the participants reported being aware of their own risk of becoming or already being HIV-positive. Consequently, the focus on alternative causes and treatment courses was often in contradiction with the information that they had about their own likelihood of having become HIV-positive. The probability of being HIV-positive themselves was usually grounded in knowing that their partner had previously been diagnosed as HIV-positive.

Some participants in relationships were aware of their sexual partner's HIV-positive status, however they were reluctant to acknowledge that they may also be HIV-positive. This was particularly common among men. They described not being ready to consider themselves ill and to accept and reconcile themselves to having an altered status of liminal health. For men in the study, for whom the act of testing and then being labelled (or self-identifying) as HIV-positive, this seemed to constitute an affront to their embodiment of masculinity through their consequent compromised strength and health. This reticence to realign their understanding of their perceived 'healthiness' further delayed the act of testing or accepting the need to start treatment.

She [his wife] would tell me to go and take a test but I would tell her that I have not yet reached that time, deep down I feared. (Male, 40 years, Uganda, WHO Stage 1)

My wife forced me...you go [laughs]. I would be in doubt but she told me to go [and test] because she tested and found that she is infected. (Male, 50 years, Uganda, WHO Stage 1)

A 46 year old woman from Zimbabwe, talked about how her husband was resisting testing when she disclosed her status that she was already initiated on ART.

I came back from the hospital and told my husband and showed him my hospital cards and he just said okay. I told him that he also must be tested because that is what they told me

at the clinic and he just said I am not sick. Each time I go for my review they ask me if he was tested and I keep on saying no and they keep on asking saying he must be tested.

The delay to act to first confirm their own positive HIV status through testing and then to initiate treatment was explained by considering that they had ‘more time’ before it became necessary to start ART. Treatment was not yet necessary because they considered that they were relatively successful in managing their symptoms, which enabled them to define the source of any ill-health as being something, anything, other than HIV. If they were still able to maintain a healthy enough body to work and get by, it was *not yet necessary* to contemplate a different course of action.

However, once they are no longer able to work, the logic of denial ceased to be productive. As such health, or at least ‘good enough’ health, is defined by *having more time*. They are still healthy enough to justify living with ambiguity about their HIV status even if they have symptoms.

The circumstances surrounding the decision to finally have an HIV test differed among participants. For some participants once they noticed that their symptoms were persistent and no longer manageable, they made a personal choice to go for HIV testing. A 43 year old man from Zimbabwe (WHO Stage 3), is an example:

But when I realized that I was not getting better I said to myself let me go and have my blood checked. The first day I went but did not get in [HIV testing rooms] and I came back but then I regretted and that night it got worse I could not sleep and I said I am going back tomorrow so I gained the courage and that's when I got tested.

However, the decision to test was commonly framed as stemming from a recognition that they no longer had the option of pursuing any other course of action. Participants described their

circumstances or the unavoidable gravity of their ill health as an irresistible pressure. Their options and 'time' were running out.

I was forced because I noticed that my health was becoming worse each day. The size I was at was reducing. I first got an illness that lasted sometime; the stomach would pain me so much but I refused to go to the hospital and instead used herbal treatment and I drank so much but the stomach refused [to get better]. (Male, 40 years, Uganda, WHO Stage 1)

Some people developed what would otherwise be very serious illnesses such as meningitis and psychiatric problems but did not relate these illnesses to HIV. In these cases, it was health workers that advised such participants to take an HIV test. For instance, a 19-year-old man from Uganda, (WHO Stage 4) was brought by his mother to the hospital. He was later tested and was found to be HIV-positive.

The head was paining very much and they removed some water [fluids] from the back [spine] and that is when the pain subsided. They diagnosed it as meningitis and started treatment. I spent two months on the ward and later a doctor took off my blood and they tested it and I was found to be HIV-positive

A 38 year old man from Uganda (WHO Stage 4) had a similar experience after complaining of a headache and developing complications:

But the problem was severe headache, so I was put on drip, I spent the night there as they put me on the drug. Then in the morning they examined my back and took off some water [fluids] from the spine and tested it and they told me that I had meningitis.

There was a sub-group of participants who had already tested at an earlier point (months or sometimes years before) but had not taken up the opportunity for treatment until they joined this

trial. There were instances where the delays between testing and treatment were attributed to a lack of available treatment options, delays in laboratory monitoring or the return of CD4-test results or patients did not pursue a referral. However, for all of those who had previously received a positive test result, they had not considered that initiating treatment was urgent. So, a similar logic applied, even among those who had tested: until they got ill to the extent that it was unmanageable, they had more time.

Having encountered problems accessing CD4 tests, many waited until they became sick before returning to seek any further care. In some cases, this meant considerable time had elapsed between receiving a positive test result and having a CD4- test done and then starting ART.

There were some exceptions to this where individuals had initially received a positive test result and had a CD4 result which was, at that time, above the threshold for initiating ART. However, the pattern was that individuals were waiting until they became sick to re-engage with care. Clinically they were then classified as 'late presenters'. A 53 year old woman from Zimbabwe (WHO Stage 3) said that:

This year [2015] I fell sick and went to the clinic and they took a CD4 count. My results delayed coming out and I was told to come a week after, I went back after one week and I was told to come after two weeks. Then I was told I should come on a Monday and then on a Friday but I never got the results and I was getting frustrated then one nurse advised me to go to a different clinic. I then went with my husband and got tested and found that my CD4 count was 55 on the same day.

It's 'about time': listening to others

In all cases seeking testing or treatment was constructed as prescient and unavoidable. Although in some cases, as shown above, it was described as a personal decision to seek a test and/or to initiate treatment, in many cases this 'individual' decision to pursue this course of action was shaped by partners, relatives, neighbours and friends who argued them that it was 'now time' to act. The dwindling capacity of individuals to successfully manage the symptoms without ART meant that it *became* time to listen and accept the advice of others to act. The opportunity for maintaining health tended to have already passed, what would be clinically defined as 'late', as this group of people were all symptomatic when presenting for testing. There was a gendered pattern to this.

Most of the women in our study described getting tested and agreeing to initiate ART on their own accord or through receiving standardised health care for another condition, such as through antenatal care when pregnant. There were only a few women who reported going for a test upon the direct insistence of others that they must do so.

I first got a miscarriage and was badly off. So I got some medicines from a clinic but that didn't help. Then my mother came and said you should go to a hospital and they test you. That is because I didn't have energy and had told her the problem that I got [miscarriage]. So I went to a testing centre and they tested me for HIV and found that I had it. [My mother] noticed that I didn't have energy. For me I thought it was due to the miscarriage but also my husband died and he had HIV that is why my mother told me that you have to go [and be tested]. (Female, 30 years, Uganda, WHO Stage 2)

Across our study there was a pattern that men reported tending to only acknowledge the necessity of testing once they had become debilitated by ill health and no longer effectively able to function or had been repeatedly urged to test by family members. For some, in the face of failure to treat their condition any other way, ART became necessary to restore their health.

But for me to come here, I had very serious headache, throbbing so much and I wasn't able, so the neighbours came and removed me from down where I was and they brought me to hospital. My eyes became blind and I was really going to die. They took me to some clinic and had me tested and I had HIV. (Male, 38 years, Uganda, WHO Stage 4)

Within our study, it was reported that couple-based testing was initiated by women. This was often only done after considerable resistance by the male partner and once other critical conditions were met, namely debilitated health as described above.

My wife told me that I was losing weight and that I should be tested for HIV but I was not convinced as I didn't realize it then that I was losing weight. I could still do my work. I don't know what my wife had observed because she kept saying you need to go and see a doctor but I was not sick at the time. After sometime, that's when I realized I was becoming weak and I started coughing. When I got worse that is when I went to the clinic with my wife and we were tested together for the first time (Male, 31 years, Zimbabwe, WHO Stage 1).

Present when they are symptomatic and they have run out of 'time'; when it is time to

A key factor in the delay in seeking treatment was the fears which existed around both the consequences of testing and of treatment. Although ART had been available for many years, the immediacy of being able to start treatment did not necessarily allay the significance involved in

the recalibration of self-identity and risks to the self in doing so. A 47 year old woman from Zimbabwe (WHO Stage 4) is one example:

It is difficult to accept that status [HIV-positive] even though you will be looking back at your past behaviour and you might be suspecting it but you just don't want that confirmation to say you have HIV. I once suspected it, there was a time about two years back when I got sick but was quick to dismiss it saying I have been bewitched. So, the issue of acceptance is what causes people to say ha it's not HIV but just chest pains, you will just be suspicious but one can just say I was bewitched because we Africans believe in being bewitched.

Following this logic, testing is scary because it confirms an HIV-positive status. However initiating treatment is also frightening because of the perceived related risks of being identified as HIV-positive through attending the clinic and being seen to take the pills. It was described as burdensome in terms of time, but also in the unwelcome reliance on indefinite treatment in which their health would always subsequently be mediated by medication.

An additional factor was participants' concerns about the side effects that come with taking drugs. Many participants spoke about the negative stories which circulated about the effects of ART within the community. The response to these narratives though was varied. Some described that their fears of encountering difficulties with the treatment and causing resistance acted as a motivation to adhere well to their treatment. However, others described it as having put them off wanting to start ART at all. It was the possibility of ill health that convinced them of the necessity of treatment despite their fears, not because they had been persuaded of the treatment's tolerability.

What I mostly feared was in the first place when they talked about these drugs that we take they would speak very harsh and scary words. Like, can you take ARVs; that tablet cannot go past the throat and even if it goes past, it is going to affect you and you will get transformed and become a nuisance, you will even grow a bump on the back. (Male 40 years, Uganda, WHO Stage 1)

The dilemmas that these frightening narratives provoked, which may not be widely discussed or acknowledged within the clinical community, are described by a 40 year old man from Zimbabwe (WHO Stage 3):

I hesitated to go on treatment after they [clinic staff] told me about the pills because people were saying the pills will make you mad you will not even sleep. Some people were saying you can dream about pigs and you will be shouting pigs, pigs pointing at them saying 'see those pigs' (laughs). But these issues are bad because they cause people to lose hope with the programme. People will be afraid of the programme [HIV treatment and care] because of what goes around in our communities. Even when I came here and I was given the pills I didn't want to take them but my wife was the one who insisted saying, 'you must not listen to what people say. What you want is to get better'. Plus the pain from the piles was troubling me, I then gained courage and said I want the piles to go away.

Discussion

The biomedical logic within the era of test and treat is that HIV-related illnesses are essentially avoidable. Test and treat is all about maximizing the opportunity to retain health for the HIV-positive individual who presents before they become severely sick and before their immune system is too damaged. Connected to this, onward transmission is also considered theoretically preventable as by being on treatment an individual can have an undetectable load and, if that is maintained, cannot infect others (Rodger et al., 2016). Within our sample, there were several people with substantial HIV-associated symptoms and a number with very high viral loads (Table 2), although these were not necessarily the same people.

However, our findings illustrate that the logic of the lived experience of those participating in our study is at odds with the biomedical logic of test and treat. We found that individuals do not consider themselves as presenting ‘late’ (or at least they do not prior to starting treatment), instead they present when it is absolutely necessary. The need to get onto treatment is not yet urgent if they consider themselves to have ‘more time’. There is a disparity between the clinical guidelines and the lay interpretations of our participants in what constitutes the criteria for it to be necessary to start treatment. This relates to a significant divergence in how ‘time’ is conceptualised as a resource for healthiness: how much time can be consumed once HIV-positive and still be considered ‘healthy’ without treatment. In our participants’ views the duration is more elastic and plentiful than indicated within the current clinical guidelines. In addition, the changes in clinical messaging can take time to filter through to patients and the wider community; this is compounded by the relatively rapid clinical progress (and resultant changes to thresholds for starting treatment).

It is important to note that this study was conducted in 2014-2015 during the very early stages in the shift towards the policy of test and treat in both Uganda and Zimbabwe (test and treat was available for some key populations in 2014, but for the general population the implementation of the policy change was in 2016). We acknowledge that individuals may receive faster referrals for testing and then may be more proactively encouraged to rapidly initiate ART had we conducted a similar study today. As such, our study cannot act as an evaluation of the impact of the test and treat policy on potential 'late presenters'. However, the contribution our study makes is in identifying important features of participants' experiences of time in relation to their own health, as well as their expectations of what it entails to accept that they need to start ART. These in turn offer productive explanations for why people may present 'late'. They are pertinent in informing how the message of the test and treat policy should be crafted to emphasise the advantages of starting ART as early as possible for an individual to maintain their health and protect others, in order to encourage earlier presentation amongst a greater number of people and thus optimise its success.

Importantly we found that participants' perceived sense of health may not be intrinsically disrupted by an individual's implicit assumption that they have probably acquired HIV. The disruption appears to be embedded within the confirmation of an HIV-positive status and the push to initiate treatment. We argue that the time-lag that we have noted between participants appreciating their own likely positive status and acting on it tells us three things. First, that many of our participants do not necessarily expect or anticipate perfect health, but instead they need sufficient health to continue to function and in most cases, this means still being able to work or be 'productive' in

some form. Second, and intrinsic to this, is appreciating that many people delay acting because they are not yet ready to accept their recalibrated identity (Russell et al., 2016). Starting treatment might improve their health, but initially at least it involves confronting a new identity which explicitly involves a liminal state of health. Third, there is a tenacious concern as to what the impact of the treatment will be on their 'life worlds' and so people postpone engaging with HIV care until they need to do so and this is done to restore, rather than protect or maintain, their health.

The definition of 'good enough health' for our participants is having time to act later. Having more or enough time is given as a justification for 'delaying' mostly because they feel 'healthy' and therefore can postpone testing and treatment. This has often been given as one of the reasons given by people who present late (Rangarajan et al., 2014; Siedner et al., 2015).

Considering the time that it will take to allow people to reconcile themselves to their new confirmed reality that they are HIV-positive before initiating treatment has received relatively little attention within the shift towards test and treat (Mbonye et al., 2016). For some of the participants, their hesitancy related to feeling that they needed time to think about the consequences of being HIV-positive and starting treatment. The message of ART as a route to maintain a form of 'complete' health (i.e. the absence of initial or ongoing HIV-related illnesses) rather than an opportunity to restore health (Takarinda et al., 2015), has not yet percolated throughout communities in high-prevalence settings.

In this study, there were no differences by gender in the state of health participants were in when they enrolled in the trial (nor were there differences across the three sites). All were enrolling

late, given the focus of the study, and both men and women presented when they were ill with many HIV-related symptoms. In addition, many of them had taken HIV tests and therefore knew they were HIV positive for quite some time before being enrolled onto the REALITY study. This means that they were aware of their risk but had not sought for treatment at this point. This can be attributed to treatment access because we note that from the narratives of these participants that an inability to immediately start on treatment contributed to their ill health, a finding corroborated in the work of Janet McGrath and colleagues (2012).

However, we found that women were more likely than men to endure severe symptoms for shorter periods and started treatment on their own initiative or because of antenatal care. Women also mentioned being encouraged by their friends or family to go and test once they had persistent and severe symptoms. So, while they presented 'late' in clinical terms they appeared to act more quickly than men when symptoms became severe.

Men often put off seeking care until they were left with little choice but to go and test for HIV, many times at the insistence of their partners. Some men presented with very severe illness because they had taken much longer to make the decision to test and seek for care, perhaps because of the fear of the diagnosis and the belief they were strong enough to manage their ill health (Siu, Seeley, & Wight, 2013).

Therefore, challenges in reconciling a healthy body with lifelong treatment for an illness may be particularly gendered, as has been shown elsewhere (Parrott et al., 2011; Skovdal, Campbell,

Nyamukapa, & Gregson, 2011). The messaging needs to be targeted, particularly towards men, including through workplace outreach, to confront the attitude that ART becomes a tolerable option only once they have become so ill that it substantially impedes their capacity to function and work. Testing and treatment outreach services needs to engage with local conceptualisations of masculinity which emphasise the attainment of health through ongoing productivity, even if that is supported by ongoing clinical treatment (Siu et al., 2013).

Our findings also emphasis the outdated but pernicious concerns which circulate around the side-effects of ART (Renju et al., 2017). Although many of these are now inaccurate, most of what the participants were referring to relates to the historical roots of earlier treatment where side-effects such as lipodystrophy were more common. Most treatments have now become much more tolerable, the physical signs that someone is on treatment and that ART is working are so ‘undetectable’ that for some people, including many of those in our study who presented ‘late’, the community narratives about the harsh, risky effects of treatment are not changing because they do not ‘see’ those on the more recent, effective, invisible treatments. The perverse effects of the success of more recent ART is that those on ART are invisible and so the early examples of ART side effects remain the reference point through which some people assess the risks in starting on treatment.

Failure to counteract and address these community narratives about the side effects of ART is likely to affect uptake of HIV testing and retention on treatment (Wringe, Renju, Seeley, Moshabela, & Skovdal, 2017). Again, the messaging around test and treat needs to place greater emphasis on the relative tolerability of ART, the protective opportunities of treatment as

prevention and the comparative absence of side-effects since the early days of HIV treatment availability in these settings. An essential component in incentivising early or timely initiation of ART is to emphasise the increased likelihood of not having physical markers of HIV and rendering HIV invisible if treatment is started as soon as possible.

References

- Curran, K., Ngunjiri, K., Shell-Duncan, B., Vusha, S., Mugo, N. R., Heffron, R., . . . Baeten, J. M. (2014). If I am given antiretrovirals I will think I am nearing the grave': Kenyan HIV serodiscordant couples' attitudes regarding early initiation of antiretroviral therapy. *AIDS, 28*(2), 227-233.
- Dempsey, S. J., Dracup, K., & Moser, D. K. (1995). Women's decision to seek care for symptoms of acute myocardial infarction. *Heart and Lung: The Journal of Acute and Critical Care, 24*(6), 444-456.
- Dieffenbach, C. W., & Fauci, A. S. (2009). Universal voluntary testing and treatment for prevention of HIV transmission. *Jama, 301*(22), 2380-2382.
- Hakim, J., Musiime, V., Szubert, A. J., Mallewa, J., Siika, A., Agutu, C., . . . for the REALITY Trial Team. (2017). Enhanced Prophylaxis plus Antiretroviral Therapy for Advanced HIV Infection in Africa. *New England Journal of Medicine, 377*(3), 233-245.
- Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., . . . van der Meer, J. W. (2011). How should we define health? *British Medical Journal, 343*, d4163.
- Insight Start Study Group. (2015). Initiation of antiretroviral therapy in early asymptomatic HIV infection. *New England Journal Medicine, 2015*(373), 795-807.
- Katz, I. T., & Bangsberg, D. R. (2016). Cascade of Refusal—What Does It Mean for the Future of Treatment as Prevention in Sub-Saharan Africa? *Current HIV/AIDS Reports, 13*(2), 125-130.

- Katz, I. T., Dietrich, J., Tshabalala, G., Essien, T., Rough, K., Wright, A. A., . . . Ware, N. C. (2015). Understanding treatment refusal among adults presenting for HIV-testing in Soweto, South Africa: a qualitative study. *AIDS and Behavior, 19*(4), 704-714.
- Kigozi, I. M., Dobkin, L. M., Martin, J. N., Geng, E. H., Muyindike, W., Emenyonu, N. I., . . . Hahn, J. A. (2009). Late disease stage at presentation to an HIV clinic in the era of free antiretroviral therapy in sub-Saharan Africa. *Journal of Acquired Immune Deficiency Syndromes, 52*(2), 280.
- Mbonye, M., Seeley, J., Nalugya, R., Kiwanuka, T., Bagiire, D., Mugenyi, M., . . . Kamali, A. (2016). Test and treat: the early experiences in a clinic serving women at high risk of HIV infection in Kampala. *AIDS care, 28*(sup3), 33-38.
- McGrath, J. W., Kaawa-Mafigiri, D., Bridges, S., & Kakande, N. (2012). 'Slipping through the cracks': Policy implications of delays in HIV treatment seeking. *Global public health, 7*(10), 1095-1108.
- Mocroft, A., Lundgren, J. D., Sabin, M. L., Monforte, A. d. A., Brockmeyer, N., Casabona, J., . . . De Wit, S. (2013). Risk factors and outcomes for late presentation for HIV-positive persons in Europe: results from the Collaboration of Observational HIV Epidemiological Research Europe Study (COHERE). *PLoS Medicine, 10*(9), e1001510.
- Moreno, S., Mocroft, A., & Monforte, A. (2010). Medical and societal consequences of late presentation. *Antiviral Therapy, 15*(1), 9.

- Mukolo, A., Villegas, R., Aliyu, M., & Wallston, K. A. (2013). Predictors of late presentation for HIV diagnosis: a literature review and suggested way forward. *AIDS and Behavior*, *17*(1), 5-30.
- Mutabazi-Mwesigire, D., Seeley, J., Martin, F., & Katamba, A. (2014). Perceptions of quality of life among Ugandan patients living with HIV: a qualitative study. *BMC Public Health*, *14*(1), 343.
- Parrott, F. R., Mwafulirwa, C., Ngwira, B., Nkhwazi, S., Floyd, S., Houben, R. M., . . . French, N. (2011). Combining qualitative and quantitative evidence to determine factors leading to late presentation for antiretroviral therapy in Malawi. *PloS one*, *6*(11), e27917.
- Rangarajan, S., Tram, H. N. B., Todd, C. S., Thinh, T., Hung, V., Hieu, P. T., . . . Hung, P. T. (2014). Risk factors for delayed entrance into care after diagnosis among patients with late-stage HIV disease in southern Vietnam. *PloS one*, *9*(10), e108939.
- Renju, J., Moshabela, M., McLean, E., Ddaaki, W., Skovdal, M., Odongo, F., . . . Seeley, J. (2017). 'Side effects' are 'central effects' that challenge retention in HIV treatment programmes in six sub-Saharan African countries: a multicountry qualitative study. *Sexually Transmitted Infections*, *93*(Suppl 3), e052971.
- Rodger, A. J., Cambiano, V., Bruun, T., Vernazza, P., Collins, S., van Lunzen, J., . . . Lundgren, J. (2016). Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy. *Jama*, *316*(2), 171-181. doi:10.1001/jama.2016.5148

- Russell, S., Martin, F., Zalwango, F., Namukwaya, S., Nalugya, R., Muhumuza, R., . . . Seeley, J. (2016). Finding meaning: HIV self-management and wellbeing among people taking antiretroviral therapy in Uganda. *PloS one*, *11*(1), e0147896.
- Russell, S., & Seeley, J. (2010). The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Social Science and Medicine*, *70*(3), 375-382.
- Schoenberg, N. E., Peters, J. C., & Drew, E. M. (2003). Unraveling the mysteries of timing: women's perceptions about time to treatment for cardiac symptoms. *Social Science and Medicine*, *56*(2), 271-284.
- Siedner, M. J., Ng, C. K., Bassett, I. V., Katz, I. T., Bangsberg, D. R., & Tsai, A. C. (2015). Trends in CD4 count at presentation to care and treatment initiation in sub-Saharan Africa, 2002–2013: a meta-analysis. *Clinical Infectious Diseases*, *60*(7), 1120-1127.
- Siu, G. E., Seeley, J., & Wight, D. (2013). Dividuality, masculine respectability and reputation: how masculinity affects men's uptake of HIV treatment in rural eastern Uganda. *Social Science and Medicine*, *89*, 45-52.
- Skovdal, M., Campbell, C., Nyamukapa, C., & Gregson, S. (2011). When masculinity interferes with women's treatment of HIV infection: a qualitative study about adherence to antiretroviral therapy in Zimbabwe. *Journal of the International AIDS Society*, *14*(1), 29.
- Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine*, *48*(11), 1507-1515.

- Staszewski, S., Morales-Ramirez, J., Tashima, K. T., Rachlis, A., Skest, D., Stanford, J., . . . for the Study 006 Team. (1999). Efavirenz plus zidovudine and lamivudine, efavirenz plus indinavir, and indinavir plus zidovudine and lamivudine in the treatment of HIV-1 infection in adults. *New England Journal of Medicine*, *341*(25), 1865-1873.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks: Sage.
- Strazdins, L., Griffin, A. L., Broom, D. H., Banwell, C., Korda, R., Dixon, J., . . . Glover, J. (2011). Time scarcity: another health inequality? *Environment and Planning A*, *43*(3), 545-559.
- Takahashi, L. M., Wiebe, D., & Rodriguez, R. (2001). Navigating the time–space context of HIV and AIDS:: daily routines and access to care. *Social Science and Medicine*, *53*(7), 845-863.
- Takarinda, K. C., Harries, A. D., Shiraishi, R. W., Mutasa-Apollo, T., Abdul-Quader, A., & Mugurungi, O. (2015). Gender-related differences in outcomes and attrition on antiretroviral treatment among an HIV-infected patient cohort in Zimbabwe: 2007–2010. *International journal of infectious diseases*, *30*, 98-105.
- Treves-Kagan, S., Steward, W. T., Ntswane, L., Haller, R., Gilvydis, J. M., Gulati, H., . . . Lippman, S. A. (2016). Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. *BMC Public Health*, *16*(1), 87.
- UNAIDS. (2017). Fact Sheet July 2017. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

- WHO. (2012). Guidance on couples HIV-testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples. Recommendations for a public health approach.
- WHO. (2016). Consolidated guidelines on the use of anti-retroviral drugs for treating and prevention HIV infection. Recommendations for a public health approach. 2nd.
- Wilton, R. D. (1996). Diminished worlds? The geography of everyday life with HIV/AIDS. *Health and Place*, 2(2), 69-83.
- Winchester, M. S., McGrath, J. W., Kaawa-Mafigiri, D., Namutiibwa, F., Ssendegye, G., Nalwoga, A., . . . Ayebazibwe, N. (2017). Routines, Hope, and Antiretroviral Treatment among Men and Women in Uganda. *Medical anthropology quarterly*, 31(2), 237-256.
- Wringe, A., Renju, J., Seeley, J., Moshabela, M., & Skovdal, M. (2017). Bottlenecks to HIV care and treatment in sub-Saharan Africa: a multi-country qualitative study. *Sexually Transmitted Infections*, 93(Suppl 3).