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To cite this article: Shona Horter, Janet Seeley, Sarah Bernays, Bernhard Kerschberger, Nomthandazo Lukhele & Alison Wringe (2020): Dissonance of Choice: Biomedical and Lived Perspectives on HIV Treatment-Taking, Medical Anthropology, DOI: [10.1080/01459740.2020.1720981](https://doi.org/10.1080/01459740.2020.1720981)

To link to this article: <https://doi.org/10.1080/01459740.2020.1720981>



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Published online: 20 Feb 2020.



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Dissonance of Choice: Biomedical and Lived Perspectives on HIV Treatment-Taking

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ABSTRACT

Treat-all recommends prompt treatment initiation for those diagnosed HIV positive, requiring adaptations to individuals' behavior and practice. Drawing on data from a longitudinal qualitative study in Eswatini, we examine the choice to initiate treatment when asymptomatic, the dissonance between the biomedical logic surrounding Treat-all and individuals' conceptions of treatment necessity, and the navigation over time of ongoing engagement with care. We reflect on the perspectives of healthcare workers, responsible for implementing Treat-all and holding a duty of care for their patients. We explore how the potentially differing needs and priorities of individuals and the public health agenda are navigated and reconciled. Rationalities regarding treatment-taking extend beyond the biomedical realm, requiring adjustments to sense of self and identity, and decision-making that is situated and socially embedded. Sense of choice and ownership for this process is important for individuals' engagement with treatment and care.

KEYWORDS

Eswatini; decision-making; engagement with care; HIV; Treat-all

The Treat-all approach, with the immediate offer of antiretroviral therapy (ART) following HIV diagnosis, is now implemented in many settings (World Health Organization 2016). A biomedical and social intervention, Treat-all requires modifications to behavior and practice and the active engagement of people and communities (Adam 2011; Kippax and Stephenson 2012), and assumes that individuals will adjust their behavior once informed of their condition (Beckmann 2013). This logic reflects the broader "biomedical paradigm" – the constellation of beliefs, values, techniques and skills shared by members of the health community (Ashcroft and Katwyk 2016).

The biomedical paradigm requires technical solutions and management by professionals and scientists (Bell and Figert 2015), with the pharmaceutical industry holding significant power and importance (Williams et al. 2011). This approach focuses on disease as a physical matter within the bounded realm of clinics, overlooking social contexts and the aspects to self and personhood which extend beyond the biomedical sphere (Beckmann 2013; Hickel 2012). Through the biomedical gaze, health professionals seek rational, objective, measurable indices of health, illness and treatment success, namely rates of HIV diagnosis, treatment initiation and viral suppression within Treat-all.

Individuals' decisions to engage with ART, however, are situated beyond the biomedical realm (Beckmann 2013). The prioritization of ART and physical health above other areas of life, such as

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Media teaser: What happens when public health goals contradict individuals' priorities and decisions for treatment-taking, and how do healthcare workers try to reconcile such difference?

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generating an income, providing for family, or maintaining social position, may not be realistic or possible (Kielmann and Cataldo 2010). For example, a study in South Africa and Zambia found individuals could delay ART initiation as the need to work took precedence over clinic attendance (Seeley et al. 2018). Thus, seemingly “irrational” behaviors such as not taking treatment as prescribed may be “ways in which people enact agency in the context of their day-to-day needs” (Paparini and Rhodes 2016:506). Additionally, there can be dissonance between clinical guidelines and lay interpretations of what constitutes treatment necessity (Kawuma et al. 2018). It is thus an imperative that socio-behavioral contexts and dimensions be considered, understood and integrated within Treat-all approaches (Kippax and Stephenson 2012).

According to WHO treatment guidelines, healthcare workers should discuss patients’ willingness and readiness to initiate ART, with the choice to accept, decline or defer ART lying with the individual patient (World Health Organization 2016). Patient autonomy is one of the four principles of healthcare ethics (in addition to beneficence, non-maleficence and justice), i.e. individuals should give informed consent (Gillon 1994) and have the right to choose whether or not to accept medical treatment, even if this decision is not deemed to be medically in their best interests (Cave 2017). While presenting important principles, there are competing interests to be reconciled in the practice of bioethics, with claims to universality not necessarily mapping onto the details of everyday life that shape the ethical landscape (Kingori 2013). Additionally, individuals’ choices may contradict public health goals, and healthcare workers may perceive moral responsibility regarding risk of HIV transmission to others in the community or protecting an unborn child from HIV acquisition (Vernooij and Hardon 2013). What will happen when patients’ choices conflict with public health goals, and how will the tension between these potentially differing priorities be managed?

Within Treat-all, the choice for treatment is presented as singular and linear, whereas choice involves multiple pathways that an individual may take. Individuals’ right to choose is balanced against the public health good, and the seemingly straightforward logic employed within healthcare ethics may differ from how Treat-all is implemented and experienced in reality. We aim in this article to critically engage with these questions, through examining the lived experiences of individuals seeking to make choices about when to initiate ART, and the perspectives and experiences of healthcare workers who operate at this interface.

Choice for treatment: extending beyond the biomedical gaze

Decision-making is deeply embedded in, shapes and is shaped by interactions with others, and autonomy can be considered relational (Keller 1997). For example, a study in Kenya and Uganda found individuals’ decisions for HIV testing were socially embedded, and influenced by the views of family members, partners, religious leaders, friends and others (Hardon et al. 2011). In Eswatini (formerly Swaziland), conceptions of initiating ART early, before one becomes visibly ill, and interpretations of treatment as preventing HIV transmission are “incorporated into existing socialities such as kinship relations, and should be seen in relation to specific local moral worlds” (Vernooij et al. 2016:11).

Decision-making may occur over multiple encounters, distributed over interactions with a number of different people, forms of information and technologies (Rapley 2008). Recognizing the distributed nature of decision-making facilitates moving from an overly prescriptive (and simplified) view to a more plausible set of ideas, which capture its complexity (Rapley 2008).

Following diagnosis with a chronic illness such as HIV, individuals may undertake “identity work,” involving coming to terms with their diagnosis and resultant changes to their sense of self and health identity (Exley and Letherby 2001; McGrath et al. 2014; Roth and Nelson 1997). Polak (2017) describes the identity work involved in individuals’ decisions to take statins, and how resisting medication can be portrayed as resisting an illness label. Identity work also involves managing a perceived “spoiled identity” (Goffman 1963), as individuals take steps to conceal information which can be discrediting. ART offers the potential to facilitate this through preventing

the development of HIV-related symptoms which may render one's status visible (Horter et al. 2019). Nguyen (2005) proposed the concept of "therapeutic citizenship," considering changes in identity that arise through interactions with biomedical authorities, and as people with HIV appropriate ART as a set of rights and responsibilities. However, ART can serve as a daily reminder of ill-health, and those who feel healthy and "normal" may want to protect that state of being, thereby resisting treatment-taking (Persson et al. 2016). "Many individuals may simply choose not to forefront HIV as the central or defining issue in their lives" (Kielmann and Cataldo 2010:25), and people can have rational reasons for not taking ART (Pound et al. 2005).

Processes of self-management involved in living with chronic illness include adjusting to and accepting the "new normal," making sense of illness, and adjusting expectations of life and self (Schulman-Green et al. 2012). Schulman-Green et al. (2012) present taking ownership of health needs as a key component of self-management, including learning about and managing body responses, developing confidence and self-efficacy for managing the condition and its treatment.

We build upon the work of Rapley and Schulman-Green to examine how individuals in Eswatini decide to initiate ART under Treat-all when considered asymptomatic, and how this may influence their ongoing treatment-taking and engagement with care. We juxtapose the biomedical gaze, which defines Treat-all success based on unilinear metrics such as 90-90-90 (aiming for 90% diagnosis of people living with HIV, 90% ART initiation for those diagnosed and 90% viral suppression for those on ART; UNAIDS 2014), with the lived reality of people's experiences and choices for engaging with care. Additionally, we compare healthcare workers' perspectives with those of patients.

Study methods

We draw on data from a longitudinal, qualitative study, conducted in the Kingdom of Eswatini from August 2015 to November 2017. The broader study included repeat interviews with individuals enrolled in HIV treatment and care under Treat-all, one-off interviews with healthcare workers, and observations of clinic and community activities relating to Treat-all.

Eswatini is a small, landlocked country in southern Africa, bordering South Africa and Mozambique, with a population of 1.3 million (UNESCO 2018), and the last absolute monarchy in Africa. Eswatini grapples with a high HIV prevalence (27% among adults 15–49 years), generalized epidemic, with transmission mainly through heterosexual sex (UNAIDS 2016). The Shiselweni region in southern Eswatini is largely rural. Here the Ministry of Health (MoH) and Médecins Sans Frontières (MSF) provide decentralized HIV and tuberculosis treatment and care. In October 2014, a Treat-all pilot began in Nhlhangano, aiming to contribute toward reduced HIV incidence and improved clinical outcomes for people with HIV. Treat-all was implemented nationally in October 2016.

The broader qualitative study comprised 106 interviews: including interviews with 29 people living with HIV, who were interviewed between two-four times August 2016-September 2017; and 20 interviews with healthcare workers employed in a range of positions relating to the implementation of Treat-all, in March 2017. Thirteen days of formal observations were conducted of clinic and community-based activities relating to Treat-all (including health talks, HIV testing and counseling, pre-ART counseling and adherence counseling for those with unsuppressed viral load results), August-September 2015, and March 2016. Broader ethnographic insights were generated through fieldwork conducted by the lead author in Eswatini during the period February 2015-November 2017. Interviews with healthcare workers and observations were conducted by the lead author, and interviews with people living with HIV were conducted by same-gender siSwati speaking research assistants, supervised by the lead author.

People living with HIV included in the study were considered clinically asymptomatic and were ineligible for treatment at the time, had it not been for the Treat-all pilot (i.e. CD4 count \geq 500 and WHO disease stage 1). Individuals were enrolled into HIV care under Treat-all, and were selected to include a gender distribution reflective of the proportion of women to men on treatment, range of ages and treatment-taking experiences (for example, those recorded lost from treatment, and those

on treatment for differing periods of time). Healthcare workers included those employed by MSF and MoH, from each of the clinics involved in Treat-all implementation (eight primary healthcare and one secondary health facilities), with a range of positions (adherence counselor, nurse/nurse supervisor, doctor).

For this analysis, four people living with HIV were selected to allow a deeper exploration of decision-making and self-management processes relating to engagement with HIV treatment and care under Treat-all. Focusing on fewer individuals enables greater detail, richness, completeness, and variance, than other analytical approaches that draw upon interviews from more people (Flyvbjerg 2013; Prior 2016). Each participant was interviewed three times over 10 months. The first interview explored their life story, including upbringing, key life events, relationships and hopes and aspirations, aiming to develop rapport and build an understanding of the participant's social and lived context. Subsequent interviews explored health management, visiting the clinic, HIV testing and diagnosis, ART offer and initiation decision-making, and ongoing treatment-taking and engagement with care. Interviews were conducted in siSwati by same-gendered interviewers, mostly at participants' homes. Following each interview, field notes were written to capture information including the interview arrangement, setting, and interviewer-interviewee dynamics. Reflection on methods, emerging themes and individual's account summaries supported the analytic process beginning from the point of data generation. Interviews were audio-recorded following written informed consent, then translated and transcribed.

These four individuals were chosen for presentation in this article as their narratives highlight a range of experiences and exemplify the type of experiences reflected in the data more broadly. We situate their narratives within the health system context by drawing upon healthcare worker interview and observational data, examining how various perspectives may confer and differ. Healthcare workers play a pivotal role in implementing Treat-all, and their narratives can provide insight to the potential tensions and dissonance between public health and individuals' goals. Interview data (transcripts and field notes) were analyzed using narrative methods, exploring how language is used to communicate meaning, how individuals construct identities through story-telling, and how accounts can be used to recount, interpret and make sense of past experiences (Riessman 2008). Additionally, changes over time in individuals' accounts were examined, through analyzing narratives within each interview and across repeat interviews for each person. Pseudonyms are used to protect individuals' confidentiality.

Findings

Zandile: adjusting to illness and ART decision-making

Zandile is 26 years old, an educated, ambitious woman who was training to be a teacher throughout our conversations with her, and hoped to be able to build a home and provide for her mother and her children. She has two young children from two relationships, having hoped both relationships would lead to marriage and then discovering each partner to be having relationships with other women, who they then went on to marry. According to her clinical record, she was diagnosed with HIV in April 2015 and initiated ART the same day as her diagnosis. This diagnosis came as a shock to her.

Zandile's narrative highlights how difficult processing an HIV diagnosis can be. She described herself as being Christian, "well behaved" and never thinking she would have HIV. During the first interview in September 2016, she said she felt she had 'fallen from Christian values' and appeared to carry a lot of self-blame and shame. She appeared to come to terms with her diagnosis in the later interviews in January and May 2017. This reflects the challenging processing of emotions that can occur following diagnosis with a chronic condition, including dealing with the shock of diagnosis, self-blame, guilt and grief, followed by making sense of illness and accepting the "new normal" (Schulman-Green et al. 2012).

Zandile's description of her diagnosis in the first interview was unprompted: we had been talking to her about her life story. She said that she "messed up," and she thinks she should have left her boyfriend, before they slept together and she became pregnant. She first attended a clinic for her pregnancy, where she was tested for HIV and tested negative. She then changed clinics and had further blood tests relating to antenatal care. In the second interview she told us that she was not informed of the results, but was just given a piece of paper, which she did not read. When she eventually saw another nurse and was told that she had been diagnosed with HIV, she said: "I felt like the hair on my head is coming off ... and as though I would get into a hole and the earth just curves in." This visceral reaction suggests this experience was a fracturing moment, one of biographical disruption (Bury 1982; Charmaz 1983).

She was advised to go for counseling, but when she got to the counseling room, she said several people were there relaxing and drinking tea, as though they were not expecting her and did not know of her situation. She found this difficult:

I am just standing there, and they said I should ask and I didn't know what to ask ... I went back there, and the nurse gave me the pills ... I was scared ... and she said, "if you start them you start for the rest of your life," and then I got so nervous ... really, I felt like I was dying and being buried at that time. They gave me huge containers of pills ... and I was carrying a mini bag, it's too small to put everything inside, and people will be looking at me, you see that when you are taking treatment people are looking at you, really, I was very low.

Zandile's description of how she felt captures the gravity and shock that accompanied the news of her positive test result, and how private information may become public property. In the context of Treat-all, a positive HIV test result is presumed to provide a final confirmation of an existing embodied sense of potential HIV positivity or risk. However, in the absence of symptoms this can be challenging (Kawuma et al. 2018; Persson 2013). HIV, or being on ART, do not appear to be normalized, certainly not immediately, as evident in Zandile's account. While HIV testing and ART initiation may be becoming increasingly routinized within the healthcare system, at an individual level it can be cataclysmic. The recognition of such a reaction is subsumed within the momentum that is integral to Treat-all. Zandile's narrative highlights the identity work that may be involved in coming to terms with and absorbing an identity related to a chronic disease. This involves adjusting to the shock of an HIV diagnosis and the threat of illness, as well as reconciling oneself to the options available for ensuring good health and keeping the illness at bay. Taking prescribed treatment can reinforce illness rather than health, with loss of control and autonomy rather than empowerment, and with shame and difference, not normalization (Pound et al. 2005). In her third interview, Zandile reflected on her initial decision not to take treatment:

When you go to the hospital and they give you Panadol [pain killer], you do not have to take it again once the headache is gone ... but these [ART] that you have to take for the rest of your life, pills every day ... and they are this big ... no, no, no, I felt like it meant I was really sick.

By the third interview she talked about how she was adjusting to her "new" self and accepting the "new normal" (Schulman-Green et al. 2012): "I decided to make HIV my friend" and spoke of not letting it have too much influence over her sense of self and her life:

I do not take note of it, I do not give myself time to think that I am positive. When I get angry, I do not then have pity and think "oh, because I am positive ..." I just don't think about it and dwell on it, it is just something I have put on its own shelf.

This reveals the continuum of identity work required in initiating and committing to sustained treatment-taking. Zandile's perception of treatment appeared to shift over time, from ART initially symbolizing illness and being potentially frightening, to later signifying a means to manage the illness and deflate the significance of HIV in her life and identity. Over time HIV may therefore come to be considered contained, rather than signified through ART (Pound et al. 2005). This process of transformation took time and will likely require ongoing work to maintain.

Decision-making can be considered as a process occurring over multiple encounters with healthcare workers, with a range of other people and technologies (Rapley 2008). When Zandile narrated her experience being diagnosed with HIV and offered ART, she highlighted multiple encounters with healthcare workers. The information she received from providers at the clinic formed part of the knowledge that she was processing toward her decision to initiate ART. She described reflecting on what the healthcare worker had told her: that she would give birth to a positive child if she did not take treatment, which she did not want and which influenced her decision to start treatment, although “it was not easy.”

Although Zandile appeared to engage with and accept treatment, she said she did not swallow the pills, but hid them in a bush near her home for around three weeks. Meanwhile, she underwent a process of thinking and seeking information. First, she told us that she spoke to her boyfriend, who was not on treatment. He advised her to re-test elsewhere as her result may not have been correct. This led her to think they were lying at the clinic, to hope he might be right, and that she might be negative, so she continued without treatment while thinking through her possible status. She also sought information on the internet, listening carefully to programs about HIV on the radio and reading relevant articles in the news. These sources of knowledge seemed to reinforce the same perspective: there is no cure for HIV, but treatment prolongs health and life.

She then contacted a pastor, seeking advice and hoping he would be able to heal her. When this pastor advised her to follow the advice at the clinic and take the treatment, she decided to start the treatment. But while the support of faith networks can provide a confirmatory catalyst for taking up treatment, there may be variation in the influence of faith, at times potentially contradicting engagement with biomedical services (Roura et al. 2010; Wringe et al. 2009).

I had just put them [ART] there and did not take them. I would listen to “HIV kills,” and I did not have any peace. I called this pastor ... because he did not know me ... I told him that at the hospital they told me this ... and the pastor said “do everything they say at the hospital, we will pray for you.” I said, “so should I take the treatment?” and he said “take them.” And that is when I started taking the treatment, I started that way.

If a person feels forced or shamed into initiating ART, and if genuine engagement and consensus is not achieved, there may be greater risk of their reversing the decision to initiate treatment, or not digesting ART despite receiving a prescription.

Sifiso: taking time to reconcile a sense of self with HIV

The identity work involved in processing an HIV diagnosis and deciding whether or when to take ART can also be seen in the story of Sifiso. Sifiso was 29 years old and studying at tertiary level when we met with him. He was recorded by the HIV clinic as being newly diagnosed in February 2015, with a CD4 count of 812, and as initiating ART two months later. However, during interviews with us in September 2016, December 2016 and June 2017, he narrated his HIV diagnosis as having occurred several years earlier. He explained that he initially doubted whether he was really HIV positive and re-tested for HIV, as though testing for the first time, to confirm his HIV diagnosis. He described eventually starting to experience signs, which he later interpreted as indicative of HIV, including weight loss, lethargy (waking up tired), chest pains and coughing. He spoke of this triggering his decision to start treatment, as he did not want his health to deteriorate further. In the second interview, Sifiso said: “I was having doubts that, do I really have it? But then again, I looked at my system that some days I would wake up tired and yet I didn’t do anything, and then I felt it’s time to take the treatment.” In the third interview he continued: “When you’re still strong there’s nothing that encourages you to start the treatment ... it’s just that you feel you’re still fit ... I was still feeling fit and that I can still continue living ... but as time goes on you realize that the immune system gets weak and so it needs something to boost it.”

Sifiso’s account of his treatment-taking decisions highlights the importance of embodied, experiential evidence indicating the need and time for treatment. This is echoed by other studies with

people living with HIV (Kawuma et al. 2018; Zhou 2016) and the conceptualisation of embodied self-regulation. Conrad (1985) found that individuals with epilepsy would interpret their physical symptoms and alter their course of treatment in order to test its efficacy, seeking evidence that the treatment was necessary and effective to motivate their taking it. We also describe the importance of individuals having evidence of treatment need and effect for motivating treatment-taking in the broader study context (Horter et al. 2019). The act of interpretation based on physical symptoms requires the passing of time for evidence to become manifest and for responsive actions to be taken, which cannot be instantaneous for those who are asymptomatic.

Celiwe: the journey to treatment readiness beginning prior to the clinic encounter

For others, the decision-making process and identity work may have begun before the initial “clinic encounter” at the point of HIV diagnosis, when each individual diagnosed with HIV is then referred for ART. Celiwe was 19 years old, married with 2 children. She completed primary school education and works at a textile factory. She was recorded as diagnosed in January 2015, and as initiating ART under a week later. She described her health seeking as initially prompted by embodied experiences that something was not right – repeated stomachache, diarrhea, weakness, weight loss. This health-seeking process was influenced by different people, in particular her mother who told her she should go to the hospital, and the healthcare worker who told her to get tested, then diagnosed her with HIV.

Although there may be a common epidemiological trend lending toward the anticipation of HIV acquisition, in the context of Treat-all in South Africa for example, acceptance of HIV-testing is constrained by poor self-assessment of HIV risk (Orne-Gliemann et al. 2016). However, Celiwe describes reflecting back on her lifestyle in conceiving her own HIV risk, which supported her coming to terms with her diagnosis and engaging with treatment. In the second interview in November 2016 she said:

When you are doing bad things, you don't think of the risk, like when I was in [city] living that life I never thought of it. But when I was sick with stomachache, it then came back to me that in [city] I was living that life and not even protecting myself, and that is when it dawned on me that it could happen that I too am like this. That is what made it easy for me to test and further accept the treatment.

This decision was influenced by other sources of knowledge, including observed experiences from her family life, as she had seen someone in her family who she knew had HIV living a “normal” life with treatment. She described the decision to initiate treatment as her “choice,” saying that healthcare workers gave her the space to make her own decision and told her that it was up to her if she wants to start them or not, as her CD4 count is high whereas if it were lower she would be “forced to start them.” While she appeared to embrace treatment, she quickly accepted her diagnosis and felt ready for treatment; her engagement with treatment appeared to be largely to resist health deterioration:

I am scared that I will become too sick maybe ... I think it is better than for me to end up dying and my children are left alone. So it is better for me to take them ... I had heard that if you are positive and do not take the treatment you could die ... I looked at having a child and if I do not start them and I fall sick and die, who will take care of my child

Nobuhle: navigating and resisting engagement with treatment and care

If the decision to initiate ART is not intrinsically based, and individuals feel coerced to test and take treatment, this can influence disengagement from care, particularly found in the context of Option B + for the prevention of vertical HIV transmission (An et al. 2015; Wringe et al. 2017). This is reflected in the story of Nobuhle, who was diagnosed with HIV during pregnancy. She described testing as “not up to you,” but as a necessity during pregnancy in order to access other pregnancy-related health services. She appeared not ready to test for HIV, and had been unable to adjust to her HIV diagnosis and undergo the identity work described by others. She did not believe her diagnosis,

having a high CD4 count and no physical “signs of HIV;” she felt she was too young to have HIV. In her second interview she described her experience of diagnosis and the offer of treatment:

It is the name [HIV], because the CD4 is high and it is just the positive word that is pointing, there are no other signs ... I will take them [ART] when I can see that it is now really there ... They [HCW] did not ask me, they told me that I will start them [ART] because I am pregnant ... They told me that when you are pregnant ... whether you like it or not you take the treatment because they say when a baby is found to be positive, you will be arrested

In her first and second interview, she told us that she was not taking the treatment; she stopped taking it after her pregnancy “because I was doing it for the child, not that I was ready to start taking treatment until I die.” As well as not believing her HIV diagnosis and need for treatment in the absence of any signs of ill health, she also had concerns about taking treatment without disclosing to her boyfriend, fearing the anticipated negative consequences of him potentially discovering her status through her treatment-taking. However, by the third interview she had reengaged with treatment, re-testing and starting afresh at a different clinic to avoid healthcare workers assuming she would stop again if she told them her treatment history and that she already knew her status. She said that she now felt ready for treatment and did not want to become sick and bedridden; when she felt she may not be able to fully recover. She also described embodied changes including weight loss and feeling as though she was not recovering physically, as influencing her decision to reengage with treatment:

Instead of recovering, I kept on losing more weight. Only to find that even the CD4 count was less, from what it was, they had dropped drastically ... I feel like I am ready now.

The resolution of identity undertaken through engaging with treatment, working to reconcile a spoiled identity, is described by Camlin and colleagues (Camlin et al. 2017) in Kenya and Uganda. Nobuhle’s story extends the concept of therapeutic citizenship, showing how this may be threatened by refusing or delaying ART initiation, which she described being positioned as “breaking the law.” This illuminates contrary currents wherein Treat-all is based primarily on a notion of patient compliance rather than patient choice, and there is a thorniness with how healthcare ethics may translate in practice. In this context, taking an alternative route, such as wanting more time before initiating ART, is characterized as resistance, and could potentially contribute to an additional spoiled identity (Goffman 1963) through subverting the expected order.

Dissonance between policy and patient priorities: healthcare worker perspectives

Individuals’ experience in coming to terms with an HIV diagnosis and deciding when to start ART is complex. However, this is not necessarily accounted for within the biomedical gaze, with unilinear metrics measuring Treat-all implementation success requiring almost all those diagnosed HIV positive to initiate treatment within a short timeframe.

Healthcare workers’ accounts highlight how providers straddle, and try to reconcile, the differing demands and priorities of patients and public health policy. Healthcare workers unanimously describe a strong desire to support patients to achieve good health outcomes and a positive life with and beyond HIV, demonstrating empathy and flexibility in caring for patients. Their accounts are interwoven with descriptions of their perceived pressure to meet targets and ensure patient “compliance” in successfully implementing Treat-all. Healthcare workers also recognize that some patients cannot be “convinced,” and they cannot force patients to engage or take treatment once they are home.

The regional and national monitoring events at which each clinic’s achievements are displayed and judged were described, where questions are asked as to why staff have not initiated all those who had been diagnosed HIV positive. Healthcare workers felt they must demonstrate their competency in testing and initiating patients, and several appeared to blame themselves and their abilities if they were not able to “convince” patients to “comply.” This echoes Vernooij and colleagues’ finding

(2013) that healthcare workers felt they would be judged as having failed if a woman refused an HIV test during antenatal care. One clinic nurse told us:

We know that counselling takes time and convincing someone takes a lot of effort. If only the program would allow and not judge us like we have failed. They make sure that they are following us, just to see what are we doing about it.

Healthcare worker accounts highlighted how this pressure could translate to the messaging they disseminated to patients and their approach in trying to achieve good results, which appeared to be particularly acute for pregnant women, as healthcare workers felt additionally responsible for the health of the child. A nurse at a different clinic explained:

Maybe we are coercing them too much ... because they are already forced to come to the facility for antenatal care, so when they come for antenatal care, every time they come you have to force them, "you have to start the ART." So they felt no, the best thing is to take the tablets and put them at home so that you will think I'm taking them while I'm not, because they felt they were forced.

This highlights the complexity of healthcare ethics in reality, and how an individual's right to choose is navigated and balanced with healthcare workers' trying to encourage and ensure what is "best" for the greater good. The sense of greater good, and the perceived responsibility for upholding and protecting it, may have differing parameters and scales, with healthcare workers potentially feeling responsible for their patients, their community, or the broader community. The wider the scope, the more emphasis placed on treatment as prevention, whereas aligning the parameters with an individual patient can heighten the tension in encouraging someone to start treatment even when they are known to not be ready. This suggests a moral dimension to treatment as prevention, whereby people living with HIV are considered at blame for potentially spreading the virus, and responsible for containing it (Bond et al. 2016), and where delayed ART initiation and sub-optimal adherence may also become morally framed (Keogh and Dodds 2015).

While patients may subscribe to the hierarchy that exists within practitioner-patient relationships, and follow healthcare worker advice, individuals are also self-determining agents who challenge and resist the structures of power and domination, with the potential to resist or rebel from following medical advice as prescribed. This action illustrates an "inherent dialectic between care and coercion within systems of discipline," and how those involved in "webs of discipline are also involved in appropriating, re-inventing and resisting techniques of power" (Vale et al. 2017:1288). If healthcare workers use their authority to control patients, they may contribute to fashioning a form of patient identity which reinforces this hierarchy (Russell et al. 2015). The clinic may offer a space within which healthcare workers can exert their authority and encourage patients to comply, but once patients leave the bounded realm of the clinic their sustained engagement relies on an individual's agency and commitment to ART.

Biomedical responsibility assumes that individuals will adjust their actions once educated, their rationality considered scientifically or biomedically based (Beckmann 2013). Patients are co-opted into a set of rigid conditions that determine treatment access and align their behavior with what is deemed "appropriate" and "healthy" (Mattes 2011), with their inclusion resting on a performance of the deserving citizen-consumer (Vale et al. 2017). Healthcare worker accounts emphasized that patients must be responsible for their lives, for their health and treatment-taking. This was reflected in counseling sessions. Blood tests to monitor patients' treatment success appeared to be appropriated as a means of ensuring patient "compliance" with treatment-taking, representing a surveillance technology and mechanism for control, encouraging patients' self-regulation of their treatment-taking to avoid detection (Foucault 1979). Within adherence counseling sessions, for example, one patient presumed to be non-adherent was told that the tests they were to run (viral load monitoring) would reveal the truth about their treatment-taking.

Many healthcare workers spoke of the emotional toll of working with large numbers of patients, and the difficulties they faced trying to encourage patients to successfully engage with treatment and care. Several highlighted the importance of patients feeling they had choice and ownership over their

health and treatment-taking, and asked for more support and understanding from programs. As one nurse said:

You cannot just give that patient treatment, they would not adhere, it's not their treatment. They need to be on the team, and actually say yes. Because if you push the treatment on them, it becomes your treatment. So, it has to be theirs, they should own it ... the whole program, they should own it, so that they keep their appointments, they take their tablets even.

Taking ownership of health needs: how sustained treatment-taking is navigated over time

Taking ownership of health needs involves learning about one's condition, managing and taking medicines, and becoming an expert (Schulman-Green et al. 2012). Additionally, individuals' perceptions of their own capacity for disease management and their beliefs about how much control they have over their health outcomes influence treatment-taking (Nafradi et al. 2017). This highlights the importance of individuals being involved in their treatment and care, taking control, and being "on the team."

Zandile spoke of the treatment-taking routine she established, and adjusting her life, so she is now used to going to the clinic regularly. She appeared to feel a sense of responsibility for her treatment-taking and for managing her health, drawing upon various approaches to continue to persevere and motivate herself to take it. She spoke with pride of how she would "stand up properly and take them." Sifiso said he felt his life was dependent upon treatment-taking, and it was of utmost importance to "be faithful to them at all times." He described ensuring he checked the time for taking his treatment, telling himself to take it and focusing on the dreams he wants to fulfil in the future that he feels treatment can help him achieve.

According to Celiwe, this was not always easy. She spoke of "begging" herself to take treatment, using her faith to find strength to persevere and reminding herself of her reasons for taking it (including to avoid death): "I just tell myself that by missing a dose I am killing myself." She said she had many difficulties taking treatment while pregnant, with morning sickness and vomiting, leading her to stop work so she could have more time to eat and then take the treatment, thereby prioritizing treatment-taking over other areas of her life (Beckmann 2013). In this she was supported by her husband and mother; this may not be the case for others.

Individuals go through complex processes in coming to terms with an HIV diagnosis, feeling ready for and deciding to initiate ART. This process is both temporally and individually varied, and an individual's priorities may differ from the priorities of the public health and biomedical agenda framing Treat-all. Healthcare workers describe the ways in which they are confronted with and try to reconcile these two agendas, recognizing the importance and underlying challenges of achieving targets for testing and initiations, and that some patients cannot be "convinced" to "comply." Several individuals described the importance of having a sense of choice regarding treatment initiation, which could potentially influence their ownership over the management of their condition, supporting their motivation for sustained treatment-taking.

Conclusion

ART initiation decision-making may involve multiple encounters, with multiple people and sources of information. The identity work and process of adapting to the "new normal" following an HIV diagnosis may take time, and can require embodied, experiential understandings of the need for treatment, additional to the sources of knowledge that may be experienced and received. Some individuals engage with HIV testing services having already begun or undergone these processes and feeling ready for the chance of an HIV diagnosis and lifelong treatment. Others need more time, and tailored information to support this. Once individuals feel they have come to terms with their diagnosis and have chosen to engage with treatment and care for themselves; their ownership of health needs can foster determination and self-responsibility to navigate and overcome challenges with treatment-taking, supporting sustained engagement with care.

Healthcare workers may experience pressure to achieve successful Treat-all implementation and meet targets for patient “compliance.” Greater understanding of the challenges patients can face coming to terms with an HIV diagnosis, starting and continuing on ART, and the challenges healthcare workers can face in supporting patients on this journey, will hopefully enable an environment conducive toward supportive practitioner-patient relationships and service delivery tailored to individuals’ needs. Allowing healthcare workers to engage with the logic of different individuals, which for some will involve time to consider the benefits of treatment according to their own rationale, could be important for their sustained engagement. Coercion to undertake testing or treatment may undermine people’s engagement with care, while conversely choice and ownership may support sustained engagement.

Acknowledgments

The Eswatini Scientific and Ethics Committee, the MSF and London School of Hygiene and Tropical Medicine Ethics Review Boards granted ethical approval before study commencement.

Thank you to all the individuals who participated in this research, and shared their time, stories and views, which enabled insight and understanding towards how Treat-all is experienced in this context. Particular thanks to Zanele Thabede and Velibanti Dlamini for contributing towards data generation and analysis, and thanks to all of the MSF and MoH staff members who supported this research. Thanks to Alexandra Wharton-Smith, David Etoori (LSHTM), Barbara Rusch and Iza Ciglenecki (MSF) for reviewing the manuscript and providing intellectual input.

Disclosure statement

The authors declare no conflict of interest

Funding

This research was funded under routine operations of Medecins Sans Frontieres.

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