



# HHS Public Access

Author manuscript

*Afr J AIDS Res.* Author manuscript; available in PMC 2018 March 01.

Published in final edited form as:

*Afr J AIDS Res.* 2017 March ; 16(1): 19–29. doi:10.2989/16085906.2017.1285795.

## Conceptions of agency and constraint for HIV-positive patients and healthcare workers to support long-term engagement with antiretroviral therapy care in Khayelitsha, South Africa

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### Abstract

In the context of the optimism around antiretroviral therapy (ART) as prevention of HIV/AIDS, addressing the barriers to long-term ART adherence is critical. This is particularly important given the tendency to individualise or use a blame discourse when exploring why HIV-infected patients “fail” to adequately adhere to ART, and not sufficiently exploring contextual reasons for poor adherence that may require varying solutions. This study took place at three clinics and one hospital in Khayelitsha, South Africa, to document the contextual factors that challenged ART adherence in this community. Interviews were conducted with 20 HIV-infected patients who had defaulted on their ART and were subsequently admitted to Khayelitsha hospital for clinical complications, and 9 ART service providers including doctors, nurses and HIV counsellors. Interviews assessed the reasons patients defaulted on ART and explored ways this could be prevented. Data from both groups were analysed collectively using thematic analysis. While the interviews revealed a landscape of environmental risks threatening adherence to ART, all patients managed to overcome the identified barriers at some point in their treatment phase, indicating the fluidity of patients’ needs and decision making. Patients reported that distrustful relationships with service providers could inhibit their understanding of ART and/or interrupt their follow-up at clinics. Patients described their rationale and agency underlying non-adherence, such as testing their bodies’ physical limits without ART medication. The study speaks to the need to appreciate contextual social and structural barriers related to ART adherence, and how these are negotiated differently by specific sub-groups, to support an appropriate response. It is imperative to not solely emphasise loss to follow-up but also assess patients’ subjective trajectory of their ART journey,

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decision making and agency with adhering to ART, their relations with healthcare workers, and how these dynamics are intertwined with broader constraints in health systems.

### Keywords

adherence; ART; HIV; health systems; long-term care

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### Introduction

Optimal adherence rates to antiretroviral therapy (ART) suppresses the HIV viral load in patients' blood to undetectable levels, allows restoration of the functioning of their immune system by increasing CD4 cells, improves patients' quality of life and prevents emergence of resistance to the medication (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Moreover, large-scale provision of ART can result in population-level reductions in the transmission of HIV (Tanser, Barnighausen, Grapsa, Zaidi, & Newell, 2013). In the context of the current optimism around the potential for wide-scale coverage of ART to have a substantial global public health impact on the HIV and AIDS epidemic, identifying and addressing the interpersonal and structural barriers to long-term adherence to ART is critical. This is particularly important given the tendency to individualise or use a blame discourse when investigating why HIV infected patients "fail" to adequately adhere to ART (Kagee et al., 2011). Reasons for disengaging from ART care are also not often sufficiently explored within specific settings despite there being diverse contextual reasons for disengagement that may require varying solutions. South Africa has the largest ART programme in the world (Shisana et al., 2014), which has dramatically reduced mortality rates attributable to HIV (UNAIDS, 2012). Yet, numerous and diverse barriers to long-term engagement in ART care in South Africa have been identified, which can significantly affect such success. This paper documents the contextual factors found to impact HIV-infected patients' disengagement from ART to the point of requiring hospitalisation in Khayelitsha, South Africa, to inform discussion of how this can be prevented.

### Disengagement from ART care

Much of the literature on disengagement from ART care has focused on individual level factors including pill fatigue, side effects of the medication, substance abuse, stigma and discrimination for people living with HIV and related fear of disclosing one's status (Nelson, 2013; Kagee et al. 2011; Miller, Ketlhapil, Rybasack-Smith, & Rosen, 2010; Ogden & Nyblade, 2005). Food insecurity and poverty have been found to influence adherence due to patients' understanding that ART should not be taken on an empty stomach (McKinney, Modeste, Lee, Gleason, & Maynard-Tucker, 2014). Transport costs are a particular barrier for individuals residing in rural South Africa who typically live far away from public hospitals and clinics from which they collect their ART medication (Ojikutu, Jack & Ramjee, 2007). In South Africa, more than 60% of patients who have tuberculosis (TB) have HIV co-infection, and TB-related morbidity in HIV infected patients who are hospitalised has been shown to result in patients' disengagement from ART care (Dalal et al., 2008). Furthermore, HIV infected patients who are chronically ill can qualify for a disability grant, a state-funded monthly stipend for those deemed unable to work due to medical reasons

(Kagee et al., 2011). Due to extreme poverty and widespread unemployment in South Africa, however, disability grants are a crucial and sometimes the sole source of income, even if patients recover enough to be able to work (Nattrass, 2006). As Kagee et al. (2011, p. 85) note: “*when disability grants are tied to AIDS-related indicators, such as CD4 counts or viral load, non-adherence may become an attractive option for patients who fear losing their grant if their CD4 count were to increase.*”

If patients' immune systems are profoundly compromised with clinical AIDS-related complications when they start ART, then the dramatic health benefits of ART (what has been termed the “Lazarus” effect) may influence patients' long-term adherence (Dahab et al. 2008). While feeling much better on ART can motivate patients' long-term adherence to ART, some patients may problematically interpret this as a sign of being “free from the virus”, causing them to disengage from care (Dahab et al., 2008). Alternatively, HIV infected patients who do not experience improved physical health whilst on ART can end up losing hope and/or trust in the medication and drop out from ART care (Roura et al., 2009). Disclosure of one's status, and having emotional and economic support from family for adhering to ART has been documented as a significant predictor of likelihood for adherence (Roura et al., 2009). However, difficult circumstances in low-income countries, especially among residents in informal settlements with limited basic amenities, high rates of migration, crowded living conditions, family violence and substance abuse, often undermines the availability and quality of social support to patients (Kagee et al., 2011). Patients' preference for privacy due to HIV stigma can hinder their access to social support (Kagee et al., 2011). Misconceptions about ART can create feelings of mistrust and confusion amongst HIV infected patients, which can be further compounded by a misunderstanding that the medication cannot be taken when drinking any alcohol (Miller et al., 2010; Roura et al., 2009). Evidence suggests that heavy alcohol consumption compromises ART adherence (Hendershot, Stoner, Pantalone, & Simoni, 2009; Nakimuli-Mpungu et al., 2012); this is a concern for South Africa given the high rates of heavy drinking (WHO, 2012). In African settings where traditional medicines are often used, traditional medication can motivate HIV infected patients' disengagement from ART given the medical advice and common perception that ART and traditional medicines should not be taken simultaneously (Dahab et al., 2008; Ojikutu et al., 2007), or that HIV is caused by witchcraft and can only be treated through spiritual means or traditional remedies (Roura et al., 2009).

Health systems factors known to affect ART adherence in South Africa include long queues, a lack of privacy, attitudes and behaviours of healthcare workers, drugs being out of stock and clinics only being open during standard working hours (Bogart et al., 2013; Miller et al., 2010; Nelson, 2013). Patients, especially men, have noted the difficulty of staying in care long-term due to limited opening hours and rigid appointment times of clinics (Kranzer et al., 2010; Ware et al., 2013). The Bogart et al. (2013) study in South Africa highlighted how many patients lamented that healthcare workers were trivialising financial and other costs they incurred when accessing ART care, and described feeling disrespected by the “short-tempered” and “scolding” staff instead of feeling cared for and supported. Similarly, Ware et al. (2013) found that participants reported how healthcare providers often shouted and used bad language, which could leave patients hurt, angry, and humiliated, and result in them

interrupting their attendance at clinics to collect their ART medication. The harsh treatment could further lead to patients experiencing guilt and shame for disengaging from ART care after making commitments to adhere to treatment (Ware et al., 2013). Fear of the negative reaction patients may get from healthcare workers if they try to resume ART after default has been shown to prevent them from re-engaging in care (Dahab et al., 2008). Dahab et al. (2008) also found that communication barriers between patients and healthcare providers contributed to poor ART adherence, especially when patients spoke a different language from their providers. ART drugs being out of stock also hinders patients' long-term engagement with ART. For example, in a study by Miller et al. (2010), participants defaulted from ART after regularly being sent home due to shortages of medication at the clinic. The referral system when ART drugs were out of stock was unclear, so patients found it difficult to use other public healthcare facilities (Miller et al., 2010).

### Research question and context

This study assessed context-specific barriers to ART adherence and being retained in ART care among patients with a particular trajectory: those who had been adherent and stable on ART, defaulted on ART care, and then re-entered ART services via hospitalisation. This study used an inductive, grounded theory approach given the exploratory nature of this research question and the lack of existing research with the particular population of focus here. Given our interest in how social and structural environments can promote or sustain the barriers to long-term adherence, the study was guided by an interest in a syndemics approach, which articulates how health disparities emerge among certain populations disproportionately, especially those made vulnerable by the synergistic intersection of factors such as poverty, stigmatisation, racism, sexism, and other forms of structural violence and exclusion (Singer & Clair, 2003). Teasing out the interplay of individual and structural vulnerabilities was relevant to this study population residing in Khayelitsha, a township located 35 km south-east of Cape Town. Khayelitsha has limited business and retail opportunities and is one of the poorest areas of Cape Town. According to the City of Cape Town Census (2011), 74% of households have a monthly income of R3200 (US\$209) or lower; 62% of the labour force aged 15 to 64 years old are unemployed; and only 45% of households live in formal dwellings. In 2011 approximately 62% of Khayelitsha residents were migrants from the rural Eastern Cape province, which has contributed to enormous pressure on the economic infrastructure (Battersby 2011). In a study by Nleya and Thompson (2009), 61% of respondents indicated crime and unemployment, after housing, as the primary problems the area faces. Khayelitsha also has one of the highest HIV prevalence rates in the Western Cape, which according to the 2013 Antenatal Survey was 34.4% among pregnant women compared to a Western Cape prevalence of 18.7% (City Health, 2013). Furthermore, Khayelitsha has extensive HIV prevention and treatment services available as well as a strong history of activism and community mobilisation around the availability of ART and combatting stigma towards people living with HIV. Advocacy efforts have been led by the Treatment Action Campaign (TAC) in Khayelitsha and by Médecins Sans Frontières/Doctors Without Borders (MSF), which have been working in collaboration with local stakeholders in the area since 1999 to develop and implement innovative models of care for TB and HIV (MSF, 2015).

This study is expected to contribute to the literature on long-term engagement with ART by highlighting the value of acknowledging contextual barriers to long-term engagement with ART and how these interplay with individual agency and decision making. This study further recognises the fluidity of patients' ART care journeys by intentionally focusing on the perspectives of patients that managed to overcome contextual barriers to adhere to ART successfully at some point in their lives and subsequently defaulted on treatment to the point of requiring hospitalisation for clinical complications.

## Methodology

### Participants

This study took place at three community-based primary care HIV clinics (Site C, Site B and Michael Mapongwana) and an inpatient facility at Khayelitsha hospital in Khayelitsha, South Africa. Interviews were conducted with a purposive sample of 20 HIV infected patients who had defaulted on ART care and were then admitted at the hospital after developing clinical complications as a result of stopping their ART. The aim was to better understand their particular experiences, and how hospitalisations among this sub-group may be prevented. Table 1 documents demographic information of all patients interviewed including sex, age, employment, income, marital status, number of children, and type of house, and latest CD4 cells count and admission diagnosis. All patients who were admitted to the study site medical wards were screened on weekdays for the duration of a larger study (November 2013 to March 2014), which sought to understand the events leading to hospitalisation for HIV infected patients. Amongst these patients, those who had previously successfully accessed ART and subsequently interrupted care were identified and invited for an interview to assess why they disengaged from ART care. For recruitment purposes the definition of interrupting care was previously taking ART successfully at a primary care clinic for any length of time, subsequently stopping ART for any reason (excluding ART being stopped by a treating clinician due to toxicity) and being admitted to the hospital with an HIV-related medical illness at the time of the interview. Patients who had recently (within the past 3 months) restarted ART were also included in the sample; 3 out of the 20 interviewed patients had recently restarted ART before admission to hospital. One patient returned to primary care due to illness, was diagnosed with pulmonary TB and restarted ART a few weeks later. Shortly after restarting ART the patient developed acute gastroenteritis and needed hospital admission. Two patients restarted ART at their clinics and presented to hospital with disseminated TB within two weeks of restarting treatment.

A research staff member screened hospital folders of all patients admitted to the medical wards on a daily basis and identified patients who had defaulted on ART care and were subsequently admitted to Khayelitsha hospital with clinical complications. The staff member identified patients to obtain written informed consent to conduct in-depth interviews. While patients were generally keen to participate and many expressed appreciation to the staff member for taking time to understand the reasons they decided to exit care, 50% of those who met criteria for inclusion in this study were either too weak or confused to consent and be interviewed. Nine ART service providers including two doctors, three nurses and four HIV counsellors were also interviewed at the clinics and hospital where patients were

interviewed, to represent a diversity of perspectives among ART care professionals. Healthcare workers were randomly recruited through the fourth, fifth and sixth authors' contacts at the clinics and hospitals. No healthcare workers declined to be interviewed. Information on the aims, risks and benefits of the research and what would be expected was provided to all participants during the recruitment process.

## Procedures

A qualitative research design was chosen as an appropriate approach to understand and analyse respondents' subjective meaning within particular social contexts (Ulin, Robinson & Tolley, 2005), which is relevant to the study objective of uncovering how and why a sub-group of HIV infected patients disengage from ART care in specific contexts. Patient interview guides were designed by the second and final authors to probe barriers and enablers for patients adhering to long-term ART and assess why patients had defaulted to the point of requiring hospitalisation. A pilot phase with a few patients whose perspectives are not included in this paper was used to test the interview guide, and through an iterative process, the final interview topic guide was designed. The aforementioned literature on barriers to ART adherence, including staff–patient interactions, education and health literacy in the local context informed the construction of the interview questions. Questions asked included: Can you tell me a few things about your own experiences of ARV treatment?; When did you first stop taking antiretrovirals? Did you stop suddenly or did you gradually stop taking them?; What was the biggest thing that made taking antiretrovirals the most difficult for you?; and Tell me what a typical visit and interaction with the staff was like when you first started attending the clinic. Patient interviews were conducted in 2013 by the third author in isiXhosa, the primary language of participants. Interviews were not audio recorded due to initial funding constraints, but the interviewer took verbatim notes on patients' answers and overall impressions, which were shared with all the authors. Interviews with patients were all conducted at the hospital bedside or in a side room if possible and the space was made as confidential as the patient's clinical condition allowed. Patient interviews lasted on average 30 to 45 minutes.

A preliminary analysis of the patient interview data was conducted and initial findings were used to design the topic guide. The first and second authors designed the interview topic guides for healthcare providers, which assessed reasons why patients defaulted on ART with the consequence of requiring hospitalisation, and explored ways this could be prevented. Questions asked included: Are there any common traits you see in your patients who do not adequately adhere to ART and/or are retained in ART care?; Is the narrative of patients stopping ART and then eventually returning for ART familiar to you? How do you make sense of this narrative?; Regarding your HIV patients who are with you over a longer period of time, do you see any typical changes in their intent, understanding and motivation around adhering to ART? and Do you have any key recommendations and suggestions to ensure patients adequately adhere to ART and to retain patients in ART care? In 2014 the first and third authors interviewed ART service providers in private rooms in the healthcare facilities they worked in. On average, interviews lasted one hour. All interviews with healthcare workers were conducted in English, tape-recorded and transcribed verbatim.

## Data analysis

Data from patients and healthcare workers were analysed collectively using thematic analysis. Thematic networks reveal prominent themes in a text at different levels and so provide a rich, detailed and holistic account of the data (Attride-Stirling, 2001). The first author immersed herself in the data to identify patterns. After carefully reading the transcripts, the author analysed the responses to the research questions and mapped out the most important constructs shaping the participants' responses. The author deliberately worked to bracket assumptions and to build an inductive understanding of factors that participants deemed important. This ensured identification of themes that had not been anticipated during the background research. Coding was regularly discussed between the first and second authors for the sake of conceptual alignment on existing and emerging codes, with regular broader meetings with the third, fourth and last authors. Once all the text segments were given basic codes, the codes were organised into basic themes by allocating similar words or codes together. An overall interpretation of the findings of the study was formulated, explaining how the themes respond to the original study questions.

## Ethical permission

Ethical approval to undertake the study was obtained from the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (UCT HREC reference number 244/2013). Before each interview, informed written consent was obtained from participants where it was made clear that they were free to withdraw from the study or could choose to not answer certain questions at any time and without any negative consequences. Participants were informed that anonymity and confidentiality would be maintained throughout. No names or identifying information are used in this paper.

## Findings

### Contextual barriers to adherence

Certain characteristics of Khayelitsha, including the extent of migration to and from the Eastern Cape province and the high unemployment rate were identified as major challenges to patients' long-term engagement with ART care. A few patients and healthcare workers narrated how the migration patterns could mean that patients start their ART regimen in Cape Town and are unable to or unfamiliar with how to access treatment when they return to the Eastern Cape. There was general consensus from patients and service providers that poverty impeded optimal adherence, primarily because it inhibited the ability: i) to regularly attend clinics to obtain treatment due to transport costs; and ii) to have sufficient and regular access to food to take with the medication. Some of the healthcare workers suggested that some environmental barriers known to have an impact on patients' long-term adherence to ART, including poverty, cannot always be addressed by the health system, or if so, in limited ways. Nonetheless, one nurse discussed how healthcare workers should be understanding about how such environmental vulnerabilities may hinder their patients from optimally adhering to ART:

I'm driving around here and looking, the way the people are living, the harsh circumstances that people are living under. Maybe now I understand, sometimes

maybe there is no food at home and now there are these big tablets that they have to take. And now I'm thinking oh my goodness maybe that is the reason why they are so sick (Nurse).

Most patients and service providers identified HIV stigma and related discrimination as a major inhibitor of regular engagement with ART care. Several patients discussed how HIV stigma prevented them from openly disclosing their HIV status in both their home and work environments. They expressed fear of losing their jobs for disclosing their HIV status, and thus felt unable to take regular time off work to attend clinics to receive treatment. As one doctor noted:

I get patients saying to me: "If I tell my boss I have HIV, I'll be told I can't work. Or I fear my boss will be telling everyone at workplace". Despite our efforts to educate patients that they are not at risk, patients still have fear other persons might not see it like that.

One female 34-year-old patient concurred that her lack of openness with her employer about her HIV status and need to obtain treatment interrupted her clinical care:

No support. It was only me and my partner who knew about my status so every time I go to the new clinic, I have to ask permission from my employer. So I decided not to go to the clinic again.

Most patients identified a lack of support from their intimate or familial relationships, including being left by a partner for disclosing their HIV status, and denial by a family member of their HIV status. A few of the female patients spoke of being financially dependent on their partner, and feared that their partner would leave them if they disclosed their HIV status. A few participants reported being most open about their HIV status with their friends. Yet several healthcare workers noted how disclosure to co-inhabitants was critical for patients' adherence to ART as this would allow them to openly take their medication at home, especially given the noted lack of privacy in many participants' homes. Family members could encourage and remind patients to take their medication, and a few participants reported that their friends defaulted on treatment or discouraged them from adhering. Several patients noted how depression and poor mental health including stress, anger, and helplessness could hinder their ART adherence and their overall health. This was confirmed by some healthcare workers. One doctor noted the importance of paying attention to this:

With Médecins Sans Frontières MSF we started looking at adherence counselling model that's more patient centred. We found that at least 30% of patients were depressed after going through counselling. We realised using a mental health questionnaire to look for depression, anxiety, that is factored into the adherence model is absolutely necessary.

Side effects of ART and pill burden were not common or significant reasons given for defaulting on treatment, despite the wealth of literature documenting these factors as barriers to long-term care. This may be related to the fact that currently used drugs have fewer side effects and less of a pill burden as most patients are on first line ART on a fixed dose combination of one pill once a day. Fear of disclosure, poverty, lack of family support, poor



mental health and migration are familiar reasons for undermining optimal adherence to ART. Yet, the distinguishing factor among the patients interviewed in this study is that at one point they managed to overcome these barriers to successfully engage with ART for a period of time before defaulting. The identified factors that could lead to disengagement from ART have also been found to hinder initial HIV testing and linkage to care, which this sub-group of patients managed to overcome.

### **Patient and healthcare worker relations**

The interviews revealed complex, distrustful and difficult relationships between patients and healthcare workers, which could inhibit patients' understanding of ART or their ability to request support and/or interrupt their care. Perceptions of and interactions with healthcare workers were said to have far reaching implications on patients' perceptions and strategies around ART adherence. The interviews revealed strong misunderstandings among patients about a variety of issues related to ART adherence including perceptions of not being able to take ART with drugs or alcohol, poor understanding of CD4 count, resistance to ART, and first, second and third line treatment. Most patients discussed how it was difficult for them to openly communicate with healthcare workers and that they felt scared to admit to defaulting for fear of disappointing or getting into trouble with healthcare workers. This fear could dissuade patients from collecting their medication once they have missed one appointment. A few patients reported keeping all their appointments although they were not taking ART medication to maintain good relationships with the clinic staff and as a form of security should they need medical care in the future.

Particular types or personalities of healthcare workers were portrayed as being top-down, demanding or too rushed to provide time and space for patients to open up. A few patients discussed feeling more comfortable with HIV counsellors than with nurses because they were perceived as less intimidating. One HIV counsellor reiterated the notion that nurses are typically less approachable than HIV counsellors:

And we, as counsellors, are down to earth. And we normally say to them, please come to me. If you have a problem maybe at the pharmacy or wherever, come to me, I will assist and help you.

A few patients indicated not believing the healthcare workers about the necessity of taking ART for life for various reasons including that healthcare workers were trying to scare or control them, or because they started to feel healthy on the treatment. One 36-year-old female patient revealed the depth of her mistrust:

Sometimes I just thought that maybe the counsellor is lying and made me feel scared. I thought why are you saying that just for me to tell whatever was on my mind.

The data also highlight healthcare workers' dedicated efforts to recognise and counter-act the mistrust between themselves and patients. One counsellor discussed giving a patient her personal contact number so she could support the patient and her child adhering to ART. The counsellor further noted the difficulty of balancing stress, being professional and maintaining a distance from patients, while also being supportive. She also educated her

patients about the stresses of healthcare workers and why they might react harshly to their patients defaulting on ART:

I said, “why are you doing this to your child?”. “No sister I was afraid because nurses will shout at me.” Oh I was so worried. I said ‘look at me’, this lady was crying, “no one can shout at you at the clinic. You are destroying your child’s life now”. I said, “even if you are late, just come”. Sometimes you end up doing inappropriate things as a counselor because I said “take my number, I will take yours. Sometimes nurses can shout because of stress but it doesn’t mean you must stay home without medication”.

Several healthcare workers spoke of the need to be friendly, non-judgmental and understanding with patients, and asking patients to be honest about why they are having difficulties adhering in order to promote a relationship of trust and openness:

You must talk to us, you must tell us what is going on, are you maybe nauseous when you take this tablet? Or you can’t swallow it? You must tell us so we can figure out something else for you.... We want to help you guys. And really sometimes we struggle. And I say to her when you go back home [to Eastern Cape], you must tell the Sister [Nurses], maybe that “these tablets are too big I cannot drink them, you guys must help me or give me time”; don’t hide the tablets because they are for your own good (Nurse).

Some groups were said to be less likely to have a positive relationship with healthcare workers. A few healthcare workers discussed how adolescent patients often experience particular stigma in the health system because it is culturally taboo to be sexually active or because they were seen as too young to be HIV infected and taking ART. Some patients and healthcare workers regarded men as less likely to attend HIV support groups, be actively engaged with HIV counselling, or seek support for adhering to ART given that dominant forms of masculinity conflict with help-seeking and vulnerability.

A few healthcare workers noted that participants have not continued HIV counselling after starting ART, which may explain some of the miscommunication, intimidation and distrust experienced by patients. Yet, they lamented how addressing such gaps is constrained by health systems barriers and the high demands on healthcare workers to care of many patients. Some healthcare workers and patients noted how the health system constraint of long waiting times at clinics, with some visits taking several hours, could prevent patients obtaining their medication regularly.

### **Various ways of exercising agency**

To comprehensively understand reasons and pathways for patients’ disengagement from long-term ART care, it is important to examine the various ways patients exercised agency through their treatment trajectory. Although the sampled patients are assumed to have some initial belief in ART that enabled them to start with the treatment, traditional or religious values and beliefs could hinder their sustained commitment to the medication. A few participants spoke about how their religious faith meant that they could be cured from HIV

without medical treatment and related being encouraged by their pastor or church members to discontinue treatment. As one doctor similarly noted:

Churches telling people about holy waters. That was another reason people defaulted. The churches said you are cured of HIV now stop taking your treatment. Some patients will then come and ask to be retested for HIV.

Some patients discussed how they disengaged from ART care based on the recommendations that HIV could be healed by traditional healers. A few expressed their belief in witchcraft as a causal factor of HIV, which requires traditional remedies to cure. Denial of one's HIV infected status was a less common, but nonetheless identified hindrance to treatment for some individuals, and could be related to these competing forms of understanding with bio-medical knowledge.

Several patients discussed their understanding of taking ART and drugs or alcohol as mutually exclusive, and defaulting on their ART medication when they used such substances based on the understanding that this was better for their health. A few patients reported defaulting on ART after feeling better with treatment or believing they had been cured of HIV. Although both patients and healthcare workers discussed common misunderstandings on behalf of patients regarding CD4 count and viral load, more than half of all patients interviewed displayed strong awareness of and engagement with these concepts. For example, some healthcare workers discussed how many patients regularly asked them to monitor their CD4 count to ensure it did not rise to the point that they could risk losing their disability grant. A few healthcare workers and patients reported more unfamiliar reasons for disengagement from ART including patients testing their own physical limits and only taking ART when their immune systems and bodies started to fail them. A few patients described not understanding how catastrophic going off ART would be until physically experiencing it. One patient found it particularly helpful to be informed by a healthcare worker that one could become resistant to ART by defaulting.

### **Enablers of ART adherence**

Supportive partners, family and home environments were given as critical enablers for adhering to ART by both patients and healthcare workers. Both patients and healthcare workers discussed the effectiveness of support groups for offering encouragement and practical techniques, such as tips for remembering to take medication daily, for adhering to ART. Support groups critically bring together HIV infected individuals from the same environment who may encounter similar barriers to adherence. One healthcare worker noted how support groups could address patients' misunderstandings around ART management and adherence. Both patients and healthcare workers noted that women were more likely than men were to attend the support groups, and that men thus need to be more actively engaged. One doctor discussed the need for adolescent support groups to address their specific needs and vulnerabilities. Certain strategies were given by healthcare workers to support patients' adherence to ART. One doctor discussed how he gives his patients updated information about their CD4 counts during their regular blood work. He also suggested that healthcare workers use a mental health questionnaire with their HIV infected patients to assess for depression and anxiety, given how this can significantly influence adherence.

Several healthcare workers discussed the need to be proactive to recognise treatment side effects to prevent patients defaulting on ART to the point of requiring hospitalisation:

This thing can damage you if you continue taking the tablets while you feel these rashes, maybe it is damaging something inside. Sometimes they take the treatment and sometimes you find that they are reacting to Bactrim [co-trimoxazole prophylaxis] because you see the skin. I think that the nurses should tell the patients, if you see anything that you see is not right or any abnormalities you must come back to the clinic (Counsellor).

One hospital-based HIV counsellor noted how open and regular counselling could address HIV related stigma:

The counsellors must always be there for our patients because every day, there is a newly diagnosed patient and you can see even while the patient is in bed that the patient is stressed because of the stigma, yes. So I think every day, there must be somebody who is coming to talk with the patient. Take the treatment and be strong. It is not the end of the world.

Some of the enablers to ART adherence were said to require bridging support, such as a recommendation that the South African government provide more ART adherence information to the general population. A few healthcare workers discussed the need for food parcels to be provided to patients who are taking ART as not having enough food was a common reason for defaulting on treatment. A few healthcare workers stressed the need for more community workers to assess and support ART adherence at the household level.

## Discussion

This study highlights various enablers and barriers to ART adherence, and how these interact with patients' knowledge, agency, healthcare worker and patient relations and broader health system constraints. The patients sampled in this study managed to overcome the significant environmental barriers identified to successfully engage in ART care for a period of time, which indicates the fluidity of their agency with and decision making in the ART process of care. The study points to the need to consider contextual barriers related to ART adherence challenges, including those faced by specific sub-groups, to direct an appropriate response to support individuals adhering to ART. The findings also indicate the need to identify how patients understand and make decisions around engagement with ART, including how the risks of not adhering to ART may compete with other interpersonal and social risks.

Patients and healthcare workers related patients' frequent misunderstanding of concepts related to ART adherence such as CD4, viral load and resistance to ART, which indicates the necessity for more regular and interactive episodes of counselling. The fact that some patients reported personally testing their bodies and their physical need for ART indicates a poor understanding of the concept of resistance, and how this can develop through poor or irregular adherence to treatment. Some patients displayed sound understanding of ART management, including regularly monitoring their CD4 count, given their perception that optimally adhering to ART could result in them losing their disability grant. This risk is particularly salient in the context of extremely high rates of poverty and unemployment in

Khayelitsha. This reflects a misconception of the policy, as eligibility for disability grants is not meant to be determined by patients' CD4 cell count, clinical stage or presence of opportunistic infections. Nonetheless, perceptions of the disability grant policy, even if inaccurate, strongly shaped the behaviours of a few patients who aimed to be below a certain CD4 threshold, as also found in another study (Govender, Fried, Birch, Chimbindi, & Cleary, 2015). Some healthcare workers expressed their belief that a CD4 count of less than 200 was grounds for them to recommend the disability grant. The findings caution an over-emphasis on the role that misunderstandings have on non-adherence given the deliberate decisions some patients appear to make through weighing up other risks such as losing one's primary source of income.

In Khayelitsha, poverty, inadequate access to food, stigmatisation and poor social support hindered patients' long-term adherence to ART; factors outside of the scope of formal healthcare services. Long-term ART adherence may be enhanced by supporting a more holistic approach to health care within vulnerable communities such as civil society organisations addressing mental health, violence, and substance abuse problems within communities (Stall et al. 2003). Men were less open to discuss their difficulties adhering to ART, which is congruent with society's often routine depiction of men as invulnerable, and a general perception that sexual and reproductive health (SRH) clinics are women's domain; this can hinder men acknowledging health risks and seeking SRH care (Stern, Rau, & Cooper, 2014). Indeed, several studies in Southern Africa have found that men are more likely than women to delay ART (Cornell, McIntyre, & Myer, 2011) and die of AIDS as a result (Mills et al. 2009), and have a higher risk of loss to ART follow-up (Meloni et al., 2014; Wandeler et al., 2012). Although there were no youth included in this study, many healthcare workers discussed their particularly high risk of loss to followup, which has been reported elsewhere (Meloni et al., 2014). Patients' fear of getting into trouble because of missing an appointment or defaulting on treatment was given as a major reason for interrupting clinic attendance, emanating from poor relationships and mistrust between healthcare workers and patients. Ware et al. (2013, p. 8) argued that patients missing visits whether unintentionally or intentionally gradually led to a "weakened sense of connectedness, reluctance to return and ultimately disengagement from care." Fear of getting into trouble with healthcare workers could also encourage patients to maintain clinic appointments without taking the medication, which calls into question the assumption of regular clinic attendance as evidence of optimal ART adherence. The VOICE (Vaginal and Oral Interventions to Control the Epidemic) study with more than 5 000 women in South Africa, Zimbabwe and Uganda who were asked to daily adhere to a microbicide gel, the pill or a placebo similarly identified a disconnect between patients' narratives to service providers or researchers and adherence realities, and found that participants' reservations about the preventive interventions affected their adherence. After a few months the study discontinued given that more than 90% of women claimed to be complying, yet blood samples indicated only 24% were using the gel, and 30% were taking the pills (Kelto, 2014). A total of 127 participants were subsequently interviewed and expressed a wealth of concerns underlying this including that the vaginal gel might harm a woman's uterus and hinder conception, fear of discrimination for taking anti-HIV medication, beliefs that the pills and gels were giving people HIV, or that the pill could cause weight gain (Kelto, 2014).

HIV related stigma was identified as a major factor hindering patients' disclosure to family, partners and employers. Stigma was especially powerful in the home as both patients and healthcare workers discussed how some respondents skipped ART doses due to fear that unsupportive family members or friends would discover their HIV status, as has been documented elsewhere (Rao et al., 2007). Related to this, the connectedness and acceptance of one's HIV status and related difficulties provided by the support groups was given as one of the most critical enablers to ART adherence. Patients disclosing their HIV status in an unsupportive environment implied major risks of rejection and stigma, such as losing their job or partner, and it may thus be self-protection for patients to choose to not disclose their HIV status. The complex relationship between ART engagement and employment was evident as patients with secure employment indicated their difficulties securing time off to attend clinics to collect their medication. This related to the inability of the healthcare system to address the needs of patients who cannot take a day off work each month for clinic visits. Some unemployed patients related insufficient funds for transport to attend clinics or not having enough food to take the ART medication with, with a potential reliance on the disability grant.

## Recommendations

The findings suggest the importance of linking ART adherence strategies with strategies aimed at combatting the social stigma and discrimination for those living with HIV (Singer, 2009). The study also supports models of ART care to address health system barriers to ART adherence, including task shifting, that is, alleviating certain responsibilities from doctors to nurses or counsellors and decentralisation of services into communities, increasing patient self-management, simplifying ART delivery, and reducing the number of times patients have to go to the clinic and waiting times at clinics to collect the medication (Grimsrud et al., 2016). Recent systematic reviews of ART models with task shifting concluded that patients supported by nurses or community health workers have comparable outcomes to those cared for by doctors (Kredo, Adeniyi, Bateganya, & Pienaar, 2014; Suthar, Rutherford, Horvath, Doherty, & Negussie, 2014, as cited in Grimsrud et al., 2016). Task shifting and decentralisation of care has already begun in South Africa with most patients currently managed by nurses in public ART clinics. This may be crucial given the 90-90-90 target of the Joint United Nations Programme on HIV/AIDS (UNAIDS), which aims to get 90% of all HIV infected patients on ART, amounting to over 6 million South Africans, which may influence the time to deliver services and the quality of care provided to serve these numbers of patients efficiently (Bogart et al., 2013; Wilkinson, 2013). It is essential for nursing and counselling staff to be aware of potential long-term adherence challenges and how to pre-empt and address these in their patients. Longer consultation times will ensure time and space to discuss new challenges at each follow-up. Ensuring flexible, tailored and inclusive care is critical as the ART health system and retention of patients may be further burdened by the universal test-and-treat policy which began in September 2016. The policy allows for any HIV-positive person to receive antiretroviral medicine irrespective of their CD4 count.

Community-based ART adherence models have been designed to relieve the burden on primary healthcare facilities, decrease frequency and intensity of patient visits and allow for patient participation and support within communities (Grimsrud et al., 2016). Piloted by

MSF in Khayelitsha, the community-based ART Adherence Club model (MSF, 2014) provides elements that address many of the identified barriers in this study. This model allows patient groups to collect pre-packed, two-month supplies of ART treatment from community health workers either at or outside the clinic. The clubs emphasise peer support and consist of approximately 30 patients led by community healthcare workers and supported by nurses (Wilkinson, 2013). ART can be collected by a treatment buddy for every alternate visit, which reduces the frequency patients need to collect treatment from approximately five times a year to three times a year (Grimsrud et al., 2016). To join the club, individuals have to be stable on ART, defined as having been on treatment for at least a year, having a suppressed viral load and no clinical conditions requiring healthcare worker follow-up (Wilkinson, 2013). Patients can be transferred from club care back to mainstream care when clinical or adherence follow-up is required (Wilkinson, 2013). A recent study found that out of 2 113 patients enrolled in adherence clubs from 2012–2013, 71% of whom were female and 7% under 24 years of age, 94% optimally adhered to treatment and 98% had suppressed viral loads at 12 months (Grimsrud et al., 2016). There was also promisingly no difference in outcomes by gender. Increasing the ease and efficiency of access to treatment was especially relevant in Khayelitsha given the migratory population and the extent of poverty.

The extent of distrust and misunderstanding between patients and healthcare workers speaks to the need to foster open relationships between healthcare workers and patients so that patients can be honest about difficulties they may be facing for optimally adhering to ART, and have sufficient opportunities for asking questions and dialogue. For example, the findings indicated how patients may understand what the consequences of ART interruption may be in theory, but want to experience it in practice. They may not, however, be fully aware of the risks of resistance. Thus, more comprehensively integrating resistance education into HIV counselling could be helpful to address this. Healthcare workers also need to be supported to provide such counselling and care including through access to communication skills courses and human rights courses to address potential stigmatising attitudes. Healthcare workers should also be supported in their work including with regular debrief opportunities given the difficulties and potential despondency to interact with patients with harsh medical and social circumstances on a daily basis. The data also highlight the value of sub-group specific ART care and adherence strategies, including having male and youth friendly healthcare services and targeted support groups. Similar to the findings in this study, the Govender et al. (2015, p. 7) study with 1 200 ART patients in South Africa found that “the imperfect communication and implementation practices around the DG [disability grant] and the subsequent misunderstandings of its processing have impacted relationships and communication between patients and healthcare providers.” The data support the Govender et al. (2015) recommendation for more collaborative efforts between the South African Department of Social Development and Health to reduce the complexity of the disability grant application and better inform healthcare workers and patients about eligibility criteria and processes of the disability grants. The appropriateness and incentives of the disability grant for people living with HIV is an area warranting further investigation, as well as cross comparative, national level research on the scale, scope and diversity of this phenomenon.

This study supports other findings indicating the challenges of retaining patients in ART care as patient numbers grow (Grimsrud et al., 2014, Meintjes et al., 2015). Cornell et al. (2010) described national temporal trends in combined cohorts, which included 10% of all patients who initiated ART in the South African public sector. The paper clearly indicates a steep increase in loss to follow-up after ART initiation in South African clinics. A total of 64% of patients were retained in care 36 months after ART initiation, of whom approximately 24% were lost to follow up for unknown and multiple reasons, including defaulting on care. Stintson et al. (2016) found that the cumulative proportion of patients retained in the Khayelitsha cohort was 65% at 5 years and 54% at 10 years. In a cross-sectional study of an adult public sector hospital in the Western Cape, 19% of HIV infected patients who were admitted to hospital were previously on ART, but had interrupted care; the patients had started ART a median of 4.7 years previously (Meintjes et al., 2015). Meintjes et al. (2015) concluded that despite widespread ART availability, there is ongoing cost and resource burden at public sector hospitals related to HIV-associated morbidity and mortality. The HIV care continuum, also known as the treatment cascade model, outlines the sequential stages of HIV medical care that people living with HIV go through from initial diagnosis to getting connected to ART care to being prescribed ART and to finally achieving the goal of viral suppression (Gardner, McLees, Steiner, del Rio, & Burman, 2011). The model shows the proportion of individuals living with HIV who are engaged at each stage, and individuals who have ever started ART are counted as being on treatment. Although the model critically highlights the magnitude of poor engagement in ART care for test-and-treat strategies for HIV prevention, the model is limited for not sufficiently highlighting the many patients who start treatment, but do not remain on ART therapy, and those who initiate ART, subsequently default to the point of requiring hospitalisation, and then re-enter ART treatment care. The treatment cascade should be expanded to add a level of people who began and were on treatment but have defaulted, as well as people who exit and re-enter ART treatment care, are hospitalised and/or die.

## Limitations and strengths

This was a cross-sectional, not a longitudinal study, which limits our understanding of the trajectory of ART care among HIV infected patients who may be prone to recall bias. The study would have benefitted from focus groups to explore the powerful role of support groups and community-based adherence models for supporting ART engagement. Focus groups with healthcare workers would also have usefully triangulated the data from their perspectives, particularly among different groups of healthcare workers. Another limitation is that the patient interview answers were written down and not audio-recorded and transcribed. Moreover, some of the patients interviewed had reconnected with ART recently, which means we could be missing the most critical cases that do not link to care or return to health facilities. A major strength of this study is the inclusion of a patient group that conventionally is difficult to access because they are lost to follow-up. Another strength was that the interviews with patients were conducted upon their return to health services in the hospital and not in the clinics where they defaulted, and they may have thus felt less inhibited to speak frankly about their negative experiences at their clinic. The authors aimed to be reflexive, which was strengthened by fact that the third author speaks isiXhosa, has a



wealth of research experience at the clinics and Khayelitsha hospital and developed rapport with participants; a critical consideration given the sensitive topic. Moreover, the fourth, fifth and sixth authors have significant experience at the clinics and at the hospital as clinicians and researchers, which generated necessary rapport with patients and healthcare workers and helped secure access to this study population. All of the authors have extensive experience in HIV related research in South Africa.

## Conclusion

There is no “one size fits all” approach for supporting patients’ engagement with ART as seen by the complexity and diversity of patients and healthcare workers’ narratives. It is imperative for researchers to not solely emphasise loss to follow up but also assess patients’ subjective experiences of, decision making and agency with adhering to ART, the trajectory of their ART journey, their relations with healthcare workers, and how these dynamics are intertwined with broader health systems constraints. Despite the fact that ART adherence is a dynamic phenomenon, there is a dearth of investigation into adherence patterns over time including critical moments or incidents where patients default, which is a warranted area of further investigation. The same patient may require different approaches to adherence support at different times in their lifetime. Our findings highlighted the need to widen the medicalised focus of ART care to understand and address the social and structural barriers to patients’ long-term engagement with ART. As Pierre Brouard compellingly said at the Conference on Men and Masculinities at the University of Cape Town in 2013:

By setting individuals and systems up to fail, we do them and ourselves a disservice, and we become intolerant towards human frailty and blind towards structural challenges.

## Acknowledgments

This study was supported by the South African Social Science and HIV (SASH) Programme at the University of Cape Town, an initiative funded by the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health (Award #R24HD077976). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The last author was supported by the Wellcome Trust (098316), the South African Research Chairs Initiative of the Department of Science and Technology and National Research Foundation (NRF) of South Africa (Grant No 64787), NRF incentive funding (UID: 85858) and the South African Medical Research Council through its TB and HIV Collaborating Centres Programme with funds received from the National Department of Health (RFA# SAMRC-RFA-CC: TB/HIV/AIDS-01-2014). We thank the clinical and administrative staff of the Western Cape Department of Health for their support of this study. We also thank all participants for sharing their personal and sometimes sensitive experiences with us. We are grateful to Molly Chuma for her valuable contribution to the literature review.

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**Table 1**Clinical characteristics of patients interviewed ( $N=20$ )

<b>Demography</b>	<b>Indicator</b>
Sex	
Female ( $n, \%$ )	13 (65)
Age, years (med, IQR)	31 (28–34)
CD4 cells/ $\mu\text{l}^*$ (med, IQR)	69 (18–245)
Employment status	
Unemployed ( $n, \%$ )	15 (75)
Formal employment ( $n, \%$ )	4 (20)
Informal employment ( $n, \%$ )	1 (5)
Main source of income	
Employment ( $n, \%$ )	4 (20)
Social grant ( $n, \%$ )	7 (35)
Family support ( $n, \%$ )	3 (15)
None ( $n, \%$ )	6 (30)
Marital status	
Married ( $n, \%$ )	6 (30)
Single ( $n, \%$ )	11 (55)
Unknown ( $n, \%$ )	3 (15)
Number of children (med, IQR, range)	1 (0–2, 0–5)
Type of house:	
Formal housing ( $n, \%$ )	9 (45)
Informal housing ( $n, \%$ )	8 (40)
Unknown ( $n, \%$ )	3 (15)
Admission diagnosis	
TB ( $n, \%$ )	13 (65)
Pneumonia ( $n, \%$ )	3 (15)
Other $^{**}$ ( $n, \%$ )	4 (20)

\* CD4 count at time of admission or latest CD4 count taken within two months before hospital admission

\*\* Deep vein thrombosis, Kaposi's sarcoma, renal failure and gastro-enteritis