

Between empathy and anger: healthcare workers' perspectives on patient disengagement from antiretroviral treatment in Khayelitsha, South Africa - a qualitative study

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Abstract

Background & objectives

The benefits of long-term adherence to antiretroviral treatment (ART) are countered by interruptions in care or *disengagement* from care. Healthcare workers (HCWs) play an important role in patient engagement and negative or authoritarian attitudes can drive patients to disengage. However, little is known about HCW perspectives on disengagement. We explored HCWs' perspectives on ART disengagement in Khayelitsha, a peri-urban area in South Africa with a high HIV burden.

Method

Semi-structured interviews were conducted in English with 30 HCWs in a primary care HIV clinic to explore their perspectives of patients who disengage from ART. Participants included doctors, nurses, counsellors, social workers, data clerks, security guards, and allied health professionals. The interview guide included questions that asked HCWs to give examples of patients who interrupt treatment, their perceptions of people who disengage from care and their feelings when dealing with a patient who is returning to care. All transcripts were audio-recorded, transcribed, and analysed using an inductive thematic analysis approach.

Results

Most staff were knowledgeable about the complexities of disengagement and highlighted potential barriers to sustaining adherence on ART, including mental health challenges and non-disclosure to family and partners. Participants expressed empathy for patients who interrupted treatment, particularly when discussing potential barriers to continued engagement in care. However, many also expressed feelings of anger and frustration towards these patients, partly because they reported these patients increase workload. Some staff, mainly those taking chronic medication themselves, perceived that patient who disengage from ART do not take adequate responsibility for their health.

Conclusion

Lifelong engagement with HIV care is influenced by many factors, including HCW interactions. Findings from this study show that staff had contradictory feelings towards disengaged patients, experiencing both empathy and anger. This understanding could contribute to the development of more nuanced interventions to support staff and encourage true person-centred care, to improve patient outcomes.

Background

The notable progress made in curbing the HIV epidemic can be attributed to innovations in prevention and treatment, and the widespread rollout of access to healthcare services for people living with HIV (PLHIV) [1]. Consequently, there has been a global reduction of up to 60% in AIDS-related deaths since the peak in 2004 [2]. However, the epidemic has not been fully conquered as nearly 38 million people are

living with HIV globally, of which only 73% are on antiretroviral therapy (ART) and 66% are virally suppressed [2]. South Africa has the largest population of PLHIV (an estimated 7.5 million) and biggest ART program in the world [2]. Although 92% of PLHIV in South Africa are aware of their status, the availability of ART has not always translated to viral suppression due to difficulties with retention in HIV care and adherence to ART at individual and systems levels [3].

Treatment interruption, or *disengagement* from treatment, has become an obstacle to the gains of ART and achieving The Joint United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 targets [2]. Poor adherence leads to several adverse consequences for both individual patients and public HIV healthcare systems, including the development of resistance to first-line medication [4, 5]. This results in people being switched to second and third-line ART regimens which have a higher pill burden, less tolerable side effects and are more expensive, making them less accessible, particularly in low and middle-income countries (LMIC) [4]. Non-adherence is also associated with a greater risk of progression to advanced HIV disease and mortality [4].

The consequences of disengagement from treatment for the individual filter into adverse impacts on the public health system. Hospitalisation due to advanced HIV disease and opportunistic infections further adds to the burden of public health in resource-limited countries [4]. A study in South Africa has shown an increasing number of patients return to care with advanced HIV disease after a period of disengagement [6]. Studies have shown that a large proportion of people with advanced HIV disease had previously been on ART and subsequently disengaged from care [6, 7, 8]. Studies have shown that the motivation for patients who cycle in and out of care to return to care is usually after severe illness or after developing complications [9, 10]. In the same light, Gao [11] used the health belief model to investigate patients' adherence based on their perception of disease severity and found that patients who experienced more symptoms were more likely to seek medical assistance. This shows that in South Africa disengagement is a growing problem that burdens the health system with more patients who require hospitalisation and extra care.

Studies show that numerous challenges contribute to disengagement from HIV treatment [12, 13, 14] or re-engaging after a period out of care. A major barrier to reengaging with treatment in sub-Saharan Africa is the punitive treatment and negative attitudes that health care workers (HCWs) have towards patients who interrupt treatment [15, 16, 17]. Moucheraud et al [18] note that HCWs serve as gatekeepers and that they impact patients' HIV care experiences, yet most adherence studies are from the patient perspective. Less is known about the perspective of HCWs, particularly in LMIC. This limits our understanding of, and approach to, optimising the management of disengagement.

Investigating HCW perspectives of disengagement could guide the development of interventions to equip HCWs with better strategies for coping with patients who disengage from treatment. Additionally, the exploration of HCW perspectives could influence the implementation of interventions that aim to improve treatment adherence and could assist in addressing some barriers to patients reengaging with treatment.

To address this critical gap in knowledge, we explored how HCWs think and feel about patients who cycle in and out of care in Khayelitsha, South Africa.

Methods

Study setting

The study was conducted at Ubuntu Clinic in Khayelitsha, a peri-urban, under-resourced area in the Western Cape Province, South Africa. Khayelitsha has a high HIV prevalence, compared to the Western Cape Province [19]. Ubuntu clinic is the biggest primary care clinic in Khayelitsha, with over 8000 PLHIV enrolled on ART [20].

The data was collected by Médecins Sans Frontières (MSF) before implementation of a differentiated service delivery (DSD) model, the Welcome Service, which aimed to better support people who return to care after treatment interruption, through a variety of tools including addressing HCWs negative attitudes and behaviours toward people who interrupt ART, as well as providing clinical and counselling training to support HCWs to be more confident and equipped in managing treatment interruption.

Study participants and data collection

The research study participants included HCWs working in the Ubuntu HIV clinic. These were doctors, nurses, counsellors, data clerks, security guards, and allied health professionals. Purposive sampling was used for the selection of participants in the study. HCWs were eligible for inclusion if they had been working at Ubuntu Clinic for more than three months and were permanently based at the clinic. All the respondents were ≥ 18 years and in capacity to give informed consent. In total, thirty participants were selected for in-depth interviews.

Permission from the Ubuntu Clinic management and the line managers of the participants was obtained so that the HCWs could be relieved of their duties for interviews, provided it did not interfere with patient care. HCWs were approached individually and invited to participate. Semi-structured interviews were used to collect data from the participants, and these lasted between 45 to 60 minutes. A semi-structured interview guide was used in this study and interviews were conducted mostly in English and others in isiXhosa (a local South African language).

Additionally, interviews were conducted in private rooms with one participant at a time. Before the interview, the researchers informed participants that they could refuse to answer any question that they felt uncomfortable about, could stop answering halfway through a question, withdraw their answer to a question either during or after the interview, and withdraw their participation completely either during or after the interview. With the consent of participants, the interviews were audio-recorded. In total, there were 30 participants. All interviews were transcribed and analysed.

Data analyses

Secondary qualitative data analysis of the interview transcripts was conducted using NVivo, a qualitative data analysis software. Transcripts were analysed using an inductive thematic analysis approach, following Braun and Clarke's stages of thematic data analysis [21]. All the transcripts were read thoroughly highlighting where the participants spoke about their thoughts and feelings towards patients who disengaged from treatment. Sections where the participants spoke about the reasons for disengagement according to their previous experiences with patients who disengaged from treatment were also highlighted. The highlighted text was named, and coded. Themes were developed by finding common threads from the codes. The common threads that were found were then named, becoming themes.

Ethical considerations

No identifying participant information was used in written outputs, and respondents were anonymized using an identifier.

Findings

Table 1
Demographic characteristics of study participants.

Participants	Total n (%)
<i>Gender</i>	
Female	21(70)
Male	9 (30)
<i>Age categories (years)</i>	
25–34	11 (37)
35–44	9 (30)
45–54	7 (23)
55+	2 (7)
Missing information	1 (3)
<i>Occupation</i>	
Support staff (management, clerks, pharmacists, data capturers, security officers, counsellors, facilitators, social workers, occupational therapists)	20 (67)
Clinicians (doctors, nurses)	10 (33)
<i>Employed by</i>	
Department of Health (DoH)	18 (60)
Non-governmental organisation (NGO)	12 (40)
<i>Time in the HIV field (years)</i>	
< 1	8 (27)
1–5	7 (23)
6–10	4 (13)
> 10	11 (37)
<i>Time at Ubuntu clinic (years)</i>	
< 1	10 (33)

Participants	Total n (%)
1–5	7 (23)
6–10	7 (23)
> 10	6 (20)

Demographic characteristics

Demographic characteristics presented in Table 1 show that the study participants comprised thirty health facility staff, most of which were support staff. Participants' ages ranged from 25 years to 65 years with most being between 35 and 44 years. There was a balance in terms of those who had extensive experience in working in the HIV field and those who had recently entered the field. Notably, 27% had been working in the HIV field for less than a year and 20% for more than sixteen years. With regards to time working at Ubuntu clinic, ten (33%) of the participants had been working at Ubuntu clinic for less than a year and two for more than sixteen years. Most participants were employed by the Department of Health (60%) and 40% were employed by non-governmental organisations.

Themes

Table 2 below is an overview of the themes that emerged from the data. Three prominent themes emanated (1) Disengagement is a public health problem that needs attention, (2) Understanding disengagement: HCWs express empathy, (3) Feelings towards patients who disengage from treatment: HCWs expressing anger and frustration. These broader themes are further divided into sub-themes presented fully below.

Table 2
Main themes identified in the analysis

Main themes	Subthemes
1. Disengagement is a public health problem that needs attention.	
2. Understanding disengagement: HCWs express empathy.	• Mental health challenges.
	• Non-disclosure leading to disengagement and the dilemma of disclosing the HIV status.
	• Concern for patients who disengage from treatment.
5. HCWs expressing anger and frustration.	• Frustration and anger.
	• Patients who disengage from treatment do not take responsibility for their health.
	• Patients who disengage from treatment are full of excuses.

Some words that the HCWs used in the interviews describe the feeling that they experience when dealing with patients who cycle in and out of care. These are described in Table 3.

Table 3
Categorisation of language used by participants in describing people who disengage

Description	Words used
Empathy and sympathy	“feel sorry”, “I get worried and concerned” “I feel very, very bad” “It makes me sad”
Anger and frustration	“What frustrates me” “I just want to strangle” “they make you angry” “There is a bit of frustration, there is a bit of disappointment” “I can admittedly feel irritated with the patients”

Theme 1: Disengagement is a public health problem that needs attention.

When the study participants were asked about patient disengagement from ART, most acknowledged that disengagement is a significant public health concern. Participants outlined several adverse effects of disengagement on the health system and the individual. Moreover, HCWs described the consequences of

disengagement, highlighting that disengagement is a threat to the person's health, treatment resistance, transmission risk, and burden for the health care system.

"It is a problem because like you know, like the virus becomes resistant to medication, so which is posing danger to the person who is not taking the medication". (Clinician, age 49)

Most of the participants reported that disengagement from treatment affects more than the individual due to transmission when the viral load is raised. In addition, the participants noted that disengagement results in the development of ART resistance requiring second-line treatment and the health system as patients who disengage often get sick and require hospital admission.

"It's a problem because a person will start all over and get sick and now hospitals have to [be] full because of this person who just decided to stop taking their treatment whereas they had a chance to take their treatment, so they don't get sick". (Support staff, age 38)

"I think it's a big problem having worked in ARVs for a long time it feels like we've hit like a second wave of the epidemic. Like initially, we had very sick people coming in, but nobody had been on ARVs before so you, we were picking up the patients who were the weakest and getting them on treatments. ... but now there [are] people who've been on ARVs before and stopped so it makes their treatment more complicated". (Clinician, age 42)

The participants saw disengagement from treatment as a significant and growing public health problem.

Theme 2: Understanding disengagement: HCWs express empathy.

Apart from describing disengagement as a public health problem, the participants showed an understanding of the multiple factors that influence treatment adherence. They highlighted some reasons for disengagement that were justifiable in their own perspectives. Their responses showed that they have some empathy towards patients as they acknowledge that patients may disengage from treatment due to mental health challenges and non-disclosure, which they saw as challenges for PLHIV. The participants went on to describe how non-disclosure is related to social support. Moreover, they illustrated how social support affects treatment adherence and could be linked to the stigma of disclosing. The participants showed concern for patients who disengage from treatment. The following section presents factors that lead to disengagement as noted by HCWs.

Mental health challenges.

Most of the participants stated that mental health challenges, including depression, affect the patients' ability to make decisions and contribute immensely to disengagement from treatment.

"Most of the patients that are having mental illness default their ARVs because of their poor insight or their poor judgement..... the patient comes, let's say he's HIV positive on ARVs and then develops mental illness, and then because mental illness affects their judgement and their insight when they are psychotic

and in a psychotic state, then they can't reason, they just do things that are very weird and things that are very odd to people". (Clinician, age 49)

The participants drew an association between mental illness symptoms (lack of insight, poor judgement) and adherence. The participants note that mental illnesses alter patients' thought processes and decision making, which could contribute to disengagement. The participants stated that disengagement from HIV treatment is a product of underlying mental health challenges. Therefore, they perceive mental illness to contribute to adherence and note that disengagement is not a choice, but it is behaviour that is influenced by the patient's mental health among many other challenges.

"Some are not mentally okay, maybe that could also be, that could, I could say maybe it's not a normal behaviour because they also go for depression; some they have like mental illnesses..." (Support staff, age 26)

The participants reported that disengagement from treatment reflected what the patients experience in their lives. The participants stated that when a patient is depressed, going through a rough patch or when they have lost hope in life, they are likely to disengage from treatment.

"...because she was struggling with her compliance on ARVs and TB treatment, we referred the patient for an assessment for depression and the patient was depressed because there was a lot of things that happened. So we started addressing those, she was seen by the psychologist and we started her on antidepressants." (Clinician, age 52).

HCWs associated mental health challenges and disengagement from treatment and described the different ways in which mental health can affect adherence to HIV treatment. The participants noted that for some patients, addressing the mental health challenges in turn addresses disengagement.

Non-disclosure leading to disengagement and the dilemma of disclosing the HIV status.

Non-disclosure was emphasised as one of the major reasons for disengagement and described as a "major problem", contributing to many cases of disengagement. They reported that in cases where the partner and family are unaware of the HIV status, patients were less likely to take treatment in front of them, resulting in disengagement.

"I think it's difficult disclosing and, if I haven't disclosed to my partner but every night at eight o'clock, we sit and have supper and I must take my treatment, you know?" (Clinician, age 52)

"I see a lot of patients who are not taking treatment well because of non-disclosure so they haven't told anyone at home" (Clinician, age 42).

The participants showed empathy for patients who found disclosing difficult because of their fear of stigma and lack of support. Although HCWs understood these barriers to taking HIV treatment, they emphasised the fact that HIV disclosure to partners and family can help to ensure treatment adherence.

I strongly believe if a person discloses to a person, it will be easy for that person even to take the medication because there is a support. Disclosing can be hard because your family may not understand” (Support staff, age 57).

“So, sometimes they say it’s the reason they can’t disclose because the guy now is going to dump that person because of the HIV status” (Support staff, age 42)

“I am not saying people should just talk about it if they are not yet comfortable, but they should not hide it from everyone, such as their families. I don’t think all your family members can judge you. You can even speak to your parent, privately, so you can get support in that way.” (Support staff, age 38)

The participants highlighted that disengagement is important especially to family and partners as the patients spend a lot of time with these people. Hiding their status from these significant people makes it difficult for patients to take their treatment. The HCWs acknowledged that disclosure is a challenge, showing empathy for patients. They understand the challenges that come with disengagement as one might not receive the support they anticipated.

Concern for patients who disengage from treatment.

Most of the participants reported being worried about patients when they disengage from treatment because they are aware of the adverse consequences of disengagement. The participants showed concern for patients who disengaged from treatment, and they emphasised that they are willing to help them in ways that they can.

“I get worried and concerned. I want to know the reasons so that we can tackle whatever challenges she has to overcome those challenges so that the patient can be able to take treatment”. (Support staff, 46)

The participant with the quote above expressed the need for insight into the reasons for disengagement. The participant did not only express concern for the patients, but also reflected on their role in being able to help the patient so that they can tackle the challenge of disengagement.

“I feel sorry for them because I see dangers in that, because there is a possibility that one can lose her life if she doesn’t take her medication, well especially the ARVs”. (Clinicians, age 49)

“It makes me feel sad, especially the young ones...., like yho! She’s still young to have this viral load”. (Support staff, age 28)

The quotes highlight that some participants had sympathy for patients, and they express worry for these patients and their well-being.

Theme 3: HCWs expressing anger and frustration.

HCW responses also underscored their anger and frustration towards patients who disengage from care. Generally, participants expressed feelings of frustration and anger and reported their source of these

feelings. HCW responses also underscored their anger and frustration towards patients who disengage from care.

Frustration and anger.

Most of the participants expressed frustration and anger towards patients who disengage from treatment. The participants noted that they do not understand why patients discontinued their treatment when it is lifesaving. In that light, the participants communicated that when patients do not take treatment, they are choosing not to save their own lives.

"...that's what frustrating me; and then somebody dies because of HIV. That I...I...I...I fail to understand, why they should die because they have treatment already. It's only the people who do not know, who did not know about this HIV or they did never started tablets or treatment, they never tested for HIV; then I would understand, but for somebody who started treatment and then they decided to leave and then they are sick like that and then they die, that's what frustrated me". (Clinician, age 64)

"...for example, why didn't you take your ARVs; I don't have any reason. Now you're like, well you just... I just want to strangle her... because I don't understand, I don't understand how come the person will just disengage their treatment for no reason". (Support staff, age 42)

The data shows that the source of frustration for HCWs is when some patients provide reasons or explanations for their disengagement that the participants considered unjustifiable. Some of the participants noted that they are frustrated because they put in the effort to ensure that the patients do not disengage from treatment, especially for those who cycle in and out of care. The participants noted some of their efforts do not yield the results that they expect, as patients still disengage from treatment despite their efforts.

"...you counsel them till you're blue in the face and they don't change. And then that, it gets frustrating in the end because you've got someone's who's sick where they wouldn't be if they just took their treatment... it's time consuming the fact that now when they come to the clinic, for starters they must come every month because their viral load now is high; they must attend a ROTF counselling sessions every morning before they go to pharmacy, before they're being seen by the sister or a doctor they must go to a group counselling the ROTF counselling and they will become now it will be seen and then so it's time consuming they end up going home late and they get a monthly appointment so every month they must be here". (Clinician, age 42).

The participants noted that working with patients who disengage from treatment is time consuming because they need special attention which makes the process long. The HCWs are tired and worn out as a result, most of the participants reported that patients who disengage from treatment frustrate them because they increase the workload when they are already overwhelmed.

"They're making me angry. I get angry. I want to slap them. Joh, joh, I get angry when someone defaults treatment". (Support staff, age 33)

"I think the anger could be for you know, with the patient sometimes because you get a sense this patient just doesn't care". (Clinician, age 52)

The participants used negative language that described their anger and frustration towards patients who disengage from treatment. The expression "joh, joh" adds emphasis to the extent of their frustration.

Patients who disengage from treatment do not take responsibility for their health.

Most of the study participants alluded to the notion that when patients disengage from treatment it means that they do not take responsibility for their health. The participants also noted that patients who discontinue their HIV treatment do not prioritise their health. Most of the participants emphasised that for patients to remain in treatment it is the responsibility of both the HCWs and the patient. Moreover, the participants noted that the HCWs are doing their part, but patients tend not to take responsibility for their health, which is why they disengage from treatment.

"If the nurse says or if the doctor says come back on the 8th of March, make means to come back on the 8th of March because this is your health, and you only have one life honestly... it's honestly your responsibility, your health honestly. Your health is your responsibility and then the clinicians and the doctors are there to help you; are there to support you; they're there for anything you want to ask and want to know". (Support staff, age 26)

Some of the participants stated that all they can do HCWs is to support patients so that they can adhere to their treatment, and it is the responsibility of the patient to ensure that they stay engaged in care.

"They don't take their responsibility, because I don't see the reason for patients to just drop their medication without consulting with [a] doctor". (Support staff, age 38)

"...but the patient also has a responsibility and it's not my responsibility as a healthcare worker to go and tell your boss that you must come to the clinic every month because now you have this disease". (Clinician, age 49)

The above quotes highlight that the participants of the study believe that it is ultimately up to the patient to adhere to their treatment when they take responsibility for their health. The study participants highlight that there is only so much that they can offer to the patients, but the patients need to take ownership of their lives and prioritise their health over anything else.

Patients who disengage from treatment are full of excuses.

When the participants were asked about their experience with patients who stop taking their HIV treatment and later return to care, most of the participants noted that these patients give excuses for disengaging from treatment.

"Something like they went to Eastern Cape and then they didn't, that is not a good reason to me...If they are going to and their appointments are not far from coming back and then they are going away, they

must come and report so that we give them referral letters, and then they can be sorted there” (Clinician, age 64)

HCWs think disengagement is unjustifiable, particularly as they have personal experience of navigating the challenges of taking long-term treatment themselves. Surprisingly, most of the participants who reported to have been taking chronic medication themselves were the ones who showed less understanding for patients who interrupt treatment. They spoke about adherence in a personal way, highlighting that if they are adhering to treatment then the patients should also do the same. They compared ART medication and their chronic medication where they highlighted that it is not difficult to take pills every day.

“I’m diabetic, I’m taking mine twice a day, I’ve never really forgotten because I’m like I have to take it. So, for me, it’s just an excuse... mostly excuses. ...no, not at all there’s no excuse not to take it” (Support staff, age 28).

“I don’t see why it should be fatigue from one tablet. It could be fatigued from maybe more than one tablet... I think it’s very traumatic when you are taking more than one tablet”. (Clinician, age 49)

The above quotes from study participants highlight that the participants regard some reasons for disengaging from treatment as unjustifiable. Some of these reasons they stated are travelling to the Eastern Cape, pill burden, and pill fatigue.

Discussion

This study shows that HCWs experience internal conflict as they grapple with contradictory feelings of empathy and anger towards patients who interrupt treatment. Findings underscore that HCWs understand treatment adherence and that patients are faced with different, difficult circumstances that result in them disengaging from treatment. HCWs acknowledged that disengagement is a public health problem and show concern for patients who interrupt treatment. On the other hand, there is a strong discourse that patients need to take responsibility for their health. The findings of this study show that the source of anger and frustration for HCWs is when they feel that patients are not taking responsibility for their own health.

The HCWs perceived themselves as having some responsibility in ensuring patients adhere and that they are willing to do what is in their capacity to support patients to stay engaged in treatment. This is in keeping with findings from a study that explored provider opinions about responsibility for medication adherence, where HCWs felt it is their responsibility to educate a patient and give them the proper treatment [22]. After doing this it becomes the responsibility of the patient to take medication as prescribed [22]. In our study, HCWs showed an understanding that disengagement is a problem that needs to be addressed, in line with previous studies of adherence where disengagement is regarded as a public health problem [3, 16, 24]. Knowing that HCWs see the seriousness of the problem and

acknowledge their responsibility is encouraging because it could translate into HCWs interest in being part of the solution.

HCWs express empathy when they perceive disengagement as out of patients' control, for example if owing to mental health challenges. Between 20% and 60% of HIV-positive adults suffer from some form of mental illness [23], with mental health challenges such as depression, and other negative emotions that may affect a patient's disposition and motivation to access and adhere to treatment [24, 25].

The findings show that HIV disclosure may influence access to social support that may help the person to cope better with treatment adherence. This echoes a previous study that indicated that non-disclosure is intertwined with stigma and poor social support [26]. Notably, the fear of stigma may prevent patients from confiding in others, leading to a lack of emotional support [26]. Knowing that staff understand how not disclosing impacts adherence could help inform interventions to improve engagement. Support from HCWs and counsellors may assist patients with disclosure and may equip patients with skills that can assist them when they disclose their status [27, 28]. Interventions to improve adherence should include capacitation of HCWs to better support patients who have difficulty with disclosure. A recommendation from one study was that HCWs could provide supported disclosure to help those who lack disclosure skills and to facilitate discussions about action plan that supports adherence and coping with HIV [28]. PLHIV hesitate to disclose their status due to fear of HIV-related stigma, interventions tackling stigma at different levels from family to community, could help patients feel more comfortable in disclosing [27].

In this study, there were the reasons HCWs considered to justifiable for disengagement for example mental health challenges and challenges of disclosure. However, the standard of justification that they used was their own standard and not the patients. Competing priorities such as work were not considered as justifiable reasons for disengagement. This reflects mismatched priorities between the patient and provider, with the paternalistic view of the HCWs who feel health should be the patients' primary priority, disregarding competing priorities which patients may value more. HCWs disregard these factors that might be impacting engagement for the patients. Research has shown that patient-centred care promotes adherence to treatment and leads to improved health outcomes [29]. There is a push to make care person-centred, which acknowledges people as whole people not just patients in the healthcare system and that health are just one of many competing priorities [29, 30, 31]. In this research, it shows that the healthcare environment is still very paternalistic and there is a need to introduce the person-centred approach to improve adherence to treatment.

It is apparent that while HCWs understand the complexities of adherence, they have feelings of anger and empathy when patients disengage, influenced by their cognition towards disengagement. Our findings demonstrate that HCWs' negative perceptions of disengagement, such as the feeling patients should be responsible for their own health, that they put their partners at risk of HIV or they over burden the health system when they disengage, all contribute to the stigmatizing attitudes and paternalistic behaviours that HCWs portray towards people who disengage. Drawing from the cognitive behavioural theory, cognition processes of individuals, which include assumptions, judgments, appraisals, meanings attached, and

assumptions, play a significant role in developing and maintaining emotional and behavioural responses to scenarios [32]. The HCWs stated that patients who interrupt treatment make them angry because they increase their workload, and they view these patients as not taking responsibility for their health. This contributes to their feelings of anger and frustration. HCWs impressions and opinions of adherence determinants are important as they shape patient interaction and clinical care recommendations, influencing the success of adherence interventions [18, 33].

Literature shows that HCWs treat patients who disengage from treatment harshly and mistreat them when they want to reengage [34, 35]. In some cases, the patients report “abuse” by clinical staff and in some cases HCWs punish patients by refusing to see them, making them come back the next day or seeing them last, shouting at them [34]. The source of this behaviour could be influenced by HCWs’ negative perception of patients who interrupt treatment. There is a need for interventions that address the negative feelings that HCWs might have towards patients who interrupt treatment, but that incorporate their feelings of both anger and empathy in designing the approach. The Actual event, Belief, and Consequences (ABC) model, influenced by Cognitive Behavioural Therapy (CBT), notes the first step to addressing HCWs negative interactions with patients is to recognize the source of the feelings that is the recognition of prejudices, biases, and negative thoughts [32]. According to the ABC model, to understand and manage stressful reactions is of paramount importance to attain control over automatic irrational thoughts and substitute them with rational, flexible interpretations that encourage well-being and productivity [32]. Therefore, it may be beneficial for interventions to cultivate an understanding of patients holistically so that certain generalisations do not translate into how HCWs engage with patients. Notably, addressing HCWs’ feelings of anger and frustration and promoting empathy toward patients could influence patients’ engagement and long-term retention in care [33].

In addition, health workers could be offered psychosocial support to help them deal with their feelings. Vesel [36] noted that the provision of coping and stress management techniques for HCWs helps them to persevere within difficult environments and this could potentially impact health service delivery and quality of care. We cannot forget the broader context of the system in which they function, where HCWs work in an overstretched health system with staff shortages, poor service delivery with inadequate and unaccountable managerial structures and little to no emotional support for staff [37]. Providing psychosocial support for health care workers could help them when they are working with patients who return to care and could impact the quality of service that they provide for these patients. These can be integrated into training programs for HCWs in which they can be equipped with stress management skills. Evidence from 17 studies shows that the practice of mental and physical relaxation activities led to a reduction of 23% in stress levels compared to no intervention [38]. Other forms of psychosocial support for HCWs could include having dedicated spaces where health facility staff can debrief [39]. A study with doctors showed that debriefing sessions provided emotional and social support which in turn reduced burnout among participants [39]. Concrete supervision and support for HCWs could be a form of psychosocial support for health facility staff [39].

In essence, the findings of this study are valuable as they could be translated into psychosocial support or skills-based training interventions that could help HCWs, and so help patients. Ideally, these should be integrated into a routine and ongoing training. However, in an overburdened health system, support for staff is rarely seen as a priority, despite the important role that HCWs play in patients' health behaviour and adherence.

Strengths and Limitations

This study provides valuable insight into the perspectives of HCWs towards patients who interrupt treatment which is missing in literature. The understanding of disengagement from the HCWs' perspectives can help direct the development and implementation of interventions to support staff and change the environment around them that causes them to feel frustrated. It highlights the need to address HCWs' paternalistic behaviour towards patients and encourage a more supportive and patient-centred approach to disengagement. Knowing which factors HCWs regard as justifiable could help when planning an intervention for patients as we will have an insight of which interventions the staff are likely to support; HCWs need to be on board to ensure that interventions are successful. This research was used by MSF in designing a differentiated service delivery mode to better support patients who disengage from HIV services in Khayelitsha.

This study was not able to show how HCWs feelings of empathy and anger play out during patient interactions. Future research is needed to understand how these perceptions lead to negative behaviours portrayed towards people who disengage from care.

Conclusion

HCW-patient relationships are complex, with tension within HCWs as they expressed both empathy and anger towards patients who disengage from treatment. Patient engagement with treatment involves many factors contributing to their retention and adherence. HCWs play an important role in patient empowerment and negative, punitive or authoritarian attitudes can drive patients to disengage or reduce the likelihood that they re-engage with care. Although HCWs express empathy for patients, further work needs to be done to support staff to feel less overwhelmed by patients who disengage from treatment. This could include offering more psychosocial support for HCWs, addressing the negative cycles of stigmatizing attitudes and paternalistic behaviour portrayed toward patients, as well as through capacitating HCWs to better support patients who disengage. Recognising that HCWs are gatekeepers to health care services, future interventions need to be designed to support both patients as well as the HCWs who care for them to improve ART engagement long term.

Abbreviations

ABC: Actual event, Beliefs and Consequences

ART: Antiretroviral treatment

HCWs: Health care workers

HIV: Human Immunodeficiency Virus

HREC: Human Research Ethics Committee

MSF: Médecins Sans Frontières

PLHIV: People living with HIV

UNAIDS: Joint United Nations Programme on HIV and AIDS

WHO: World Health Organization

Declarations

Ethics approval and consent to participate

This study was approved on 21 August 2020 by the Faculty of Health Sciences Human Research Ethics Committee (HREC) of the University of Cape Town (Reference: 495/2020). Written, informed consent was given by all the participants for voluntary participation. This research was conducted in accordance with the Declaration of Helsinki.

Consent for publication

Not applicable.

Availability of data and materials

The data used in this study is stored by MSF and may be made available upon request from the corresponding author.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

The Welcome Study was designed by CK, TC, KL, and NZ, with input on the qualitative design from AS. TN took the lead in analysing transcripts from interviews conducted by CK and NZ towards the completion of her Master of Public Health degree under the supervision of CS and AS. All authors reviewed and commented on multiple drafts of the article and agreed on the full version for submission.

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References

1. Jones J, Sullivan P, Curran J. Progress in the HIV epidemic: identifying goals and measuring success. *PLOS Medicine*. 2019;16(1):e1002729.
2. UNAIDS. Global HIV & AIDS statistics fact sheet. 2021. Available from: https://www.unaids.org/en/resources/documents/2021/2021_unaids_data Accessed 11 April 2022.
3. Venables E, Towriss C, Rini Z, Nxiba X, Cassidy T, Tutu S, Grimsrud A, Myer L, Wilkinson L. Patient experiences of ART adherence clubs in Khayelitsha and Gugulethu, Cape Town, South Africa: a qualitative study. *PLoS One*. 2019;14(6).
4. Moosa A, Gengiah T, Lewis L, Naidoo K. Long-term adherence to antiretroviral therapy in a South African adult patient cohort: a retrospective study. *BMC Infectious Diseases*. 2019;19(1).
5. Schaecher K L. The importance of treatment adherence in HIV. *The American Journal of Managed Care*. 2013; 1912 Suppl 1: 231–237.
6. Ford N, Meintjes G, Calmy A, Bygrave H, Migone C, Vitoria M et al. Managing advanced HIV disease in a public health approach: guideline development group for managing advanced HIV disease and rapid initiation of antiretroviral therapy. *Clinical Infectious Diseases*. 2018; 66(2).
7. Ford N, Shubber Z, Meintjes G, Grinsztejn B, Eholie S, Mills E, et al. Causes of hospital admission among people living with HIV worldwide: a systematic review and meta-analysis. *The Lancet HIV*. 2015;2(10):e438-e444.
8. Sungkanuparph S, Kiertiburanakul S, Apisarnthanarak A, Malathum K, Watcharananan S, Sathapatayavongs B. Rapid CD4 decline after interruption of non-nucleoside reverse transcriptase inhibitor-based antiretroviral therapy in a resource-limited setting. *AIDS Research and Therapy*. 2007 Dec;4(1):1–6.
9. Estill J, Ford N, Salazar-Vizcaya L, Haas A, Blaser N, Habiyambere V, et al. The need for second-line antiretroviral therapy in adults in sub-Saharan Africa up to 2030: a mathematical modelling study. *The Lancet HIV*. 2016;3(3):e132-e139.
10. Beeman A, Bengtson AM, Swartz A, Colvin CJ, Lurie MN. Cyclical engagement in HIV care: a qualitative study of clinic transfers to re-enter HIV care in Cape Town, South Africa. *AIDS and*

Behavior. 2022 Jan 21:1–0.

11. Gao X, Nau D, Rosenbluth S, Scott V, Woodward C. The relationship of disease severity, health beliefs and medication adherence among HIV patients. *AIDS Care*. 2000;12(4):387–398.
12. Croome N, Ahluwalia M, Hughes L, Abas M. Patient-reported barriers and facilitators to antiretroviral adherence in sub-Saharan Africa. *AIDS*. 2017;31(7):995–1007.
13. Duwell M, Knowlton A, Nachega J, Efron A, Goliath R, Morroni C, et al. Patient-nominated, community-based HIV treatment supporters: Patient perspectives, feasibility, challenges, and factors for success in HIV-infected South African adults. *AIDS Patient Care and STDs*. 2013;27(2):96–102.
14. Kagee A, Remien RH, Berkman A, Hoffman S, Campos L, Swartz L. Structural barriers to ART adherence in Southern Africa: challenges and potential ways forward. *Global public health*. 2011; 6(1):83–97.
15. Dapaah J. Attitudes and Behaviours of Health Workers and the Use of HIV/AIDS Health Care Services. *Nursing Research and Practice*. 2016;2016:1–9.
16. Ibrahim L, Hadjia I, Nguku P, Waziri N, Akhimien M, Patrobas P, et al. Health care workers' knowledge and attitude towards TB patients under Direct Observation of Treatment in Plateau state Nigeria, 2011. *Pan African Medical Journal*. 2014;18.
17. Zanolini A, Sikombe K, Sikazwe I, Eshun-Wilson I, Somwe P, Bolton Moore C, et al. Understanding preferences for HIV care and treatment in Zambia: evidence from a discrete choice experiment among patients who have been lost to follow-up. 2021; 15(8):1–1
18. Moucheraud C, Stern A, Ahearn C, Ismail A, Nsubuga-Nyombi T, Ngonyani M, et al. Barriers to HIV treatment adherence: a qualitative study of discrepancies between perceptions of patients and health providers in Tanzania and Uganda. *AIDS Patient Care and STDs*. 2019;33(9):406–413.
19. Stinson K, Goemaere E, Coetzee D, van Cutsem G, Hilderbrand K, Osler M, Hennessey C, Wilkinson L, Patten G, Cragg C, Mathee S. Cohort profile: the Khayelitsha antiretroviral programme, Cape town, South Africa. *International Journal of epidemiology*. 2017;46(2):e21.
20. WHO. WHO | When you have a hope. [online] Who.int.2019 https://www.who.int/hiv/mediacentre/feature_story/khayelitsha_icasa13/en/. Accessed 28 January 2021.
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006;3(2):77–101.
22. Tarn D, Mattimore T, Bell D, Kravitz R, Wenger N. Provider views about responsibility for medication adherence and content of physician-older patient discussions. *Journal of the American Geriatrics Society*. 2012;60(6):1019–1026.
23. Jonsson G, Davies N, Freeman C, Joska J, Pahad S, Thom R, Thompson K, Woollett N, Furin J, Meintjes G. Management of mental health disorders in HIV-positive patients. *Southern African Journal of HIV Medicine*. 2013;14(4):155–165.
24. Coetzee B, Kagee A, Vermeulen N. Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers. *AIDS care*. 2011; 23(2):146–

- 51.
25. Gonzalez, J., Batchelder, A., Psaros, C, Safren, S. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. *AIDS Journal of Acquired Immune Deficiency Syndromes*. 2011;58(2): 181–187.
 26. Bogart L, Chetty S, Giddy J, Sypek A, Sticklor L, Walensky R, et al. Barriers to care among people living with HIV in South Africa: Contrasts between patient and healthcare provider perspectives. *AIDS Care*. 2013;25(7):843–853.
 27. Maeri I, El Ayadi A, Getahun M, Charlebois E, Akatukwasa C, Tumwebaze D, et al. “How can I tell?” Consequences of HIV status disclosure among couples in eastern African communities in the context of an ongoing HIV “test-and-treat” trial. *AIDS Care*. 2016;28(sup3):59–66.
 28. Bikaako-Kajura W, Luyirika E, Purcell DW, Downing J, Kaharuza F, Mermin J, Malamba S, Bunnell R. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behavior*. 2006 Jul;10(1):85–93.
 29. Robinson JH, Callister LC, Berry JA, Dearing KA. Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*. 2008 Dec;20(12):600–7.
 30. Abboah-Offei M, Bristowe K, Koffman J, Vanderpuye-Donton NA, Ansa G, Abas M, Higginson I, Harding R. How can we achieve person-centred care for people living with HIV/AIDS? A qualitative interview study with healthcare professionals and patients in Ghana. *AIDS care*. 2020 Dec 1;32(12):1479-88.
 31. Bristowe K, Clift P, James R, Josh J, Platt M, Whetham J, Nixon E, Post FA, McQuillan K, Ní Cheallaigh C, Murtagh FE. Towards person-centred care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centre qualitative study with key stakeholders. *HIV medicine*. 2019 Sep;20(8):542–54.
 32. Ellis A. *Overcoming destructive beliefs, feelings, and behaviors: New directions for rational emotive behavior therapy*. Prometheus Books; 2010.
 33. Costello K, Kennedy P, Scanzillo, JO. Recognizing nonadherence in patients with multiple sclerosis and maintaining treatment adherence in the long term. *The Medscape Journal of Medicine*. 2008; 10(9):225.
 34. Layer EH, Brahmabhatt H, Beckham SW, Ntogwisangu J, Mwampashi A, Davis WW, Kerrigan DL, Kennedy CE. “I pray that they accept me without scolding.” Experiences with disengagement and re-engagement in HIV care and treatment services in Tanzania. *AIDS patient care and STDs*. 2014 Sep 1;28(9):483-8.
 35. Ware, N., Wyatt, M., Geng, E., Kaaya, S., Agbaji, O., Muyindike, W., Chalamilla, G. and Agaba, P., 2013. Toward an Understanding of Disengagement from HIV Treatment and Care in Sub-Saharan Africa: A Qualitative Study. *PLoS Medicine*, 10(1), p.e1001369.
 36. Vesel L, Waller K, Dowden J, Fotso JC. Psychosocial support and resilience building among health workers in Sierra Leone: interrelations between coping skills, stress levels, and interpersonal

- relationships. BMC health services research. 2015;15(1):1–8.
37. Malakoane B, Heunis J, Chikobvu P, Kigozi N, Kruger W. Public health system challenges in the Free State, South Africa: a situation appraisal to inform health system strengthening. BMC Health Services Research. 2020;20(1).
 38. Ruotsalainen JH, Verbeek JH, Mariné A, Serra C. Preventing occupational stress in healthcare workers. Cochrane Database of Systematic Reviews. 2014(11).
 39. Gunasingam N, Burns K, Edwards J, Dinh M, Walton M. Reducing stress and burnout in junior doctors: the impact of debriefing sessions. Postgraduate medical journal. 2015 Apr 1;91(1074):182-7.