"I am going to make tricks… whereby I am going to be a new person again": Reimagining the framework for HIV care engagement from a cascade to a cycle model

By

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ABSTRACT

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Background: Long-term patient engagement and retention in care has been an ongoing challenge within the HIV health system. Many patients who are thought to have disengaged are often categorized as "lost to follow-up" (LTFU) when in reality they may have sought care at another facility. Clinic switching may occur through formal channels of acquiring a transfer letter or informally by silently transferring. This study investigated the motivations that influence HIV-positive people to switch clinics, to understand the process of clinic switching, and to examine the components that influences a person to choose a new clinic.

Methods: We conducted semi-structured, qualitative interviews in Gugulethu, South Africa with 19 people who are HIV positive and have switched clinics at least once since starting antiretroviral therapy (ART). Transcripts were analyzed using inductive and deductive thematic coding.

Results: Among the 19 participants ten were female and nine were male and have had a HIV diagnoses on average for 14 years. 89.5% of the participants have switched clinics more than once with an average transferring four times. Participants often relayed their engagement experience in the context of a cycle using clinic switching as a tactic to regain entry into the health system. We identified five themes that relate to varying points in a patient's cycle of engagement; 1) continued barriers to care, 2) internal and external stigma to be the "perfect patient" led patients to fully disengage, 3) pull factors back into care, 4) patients "tricks" and mechanisms to navigate re-entry into care and finally 5) continued motivation to stay engaged in care.

Conclusion: These data illustrate multiple different time points within a patient cycle of engagement when focusing on long-term retention. Conventionally, HIV engagement has been

conceptualized as a linear, unidirectional treatment cascade. Our study exposes the need to understand these cycles of engagement better in order to create interventions and clinic policies to help continued engagement of new, returning, and struggling patients.

INTRODUCTION

The rollout of Antiretroviral therapy (ART) in sub-Saharan Africa has saved millions who are currently living with HIV (1-2). In recent years, large-scale programs to provide antiretroviral therapy to all people living with HIV have expanded. In 2016 the South African government launched a new policy of universal "test-and-treat" in order to expand access to all of those who are HIV positive (3). The benefits of ART are known extensively as a method for keeping individuals healthy. Furthermore, adherence to ART can virally suppress the disease, which assists in the prevention of onward transmission of the virus, helping to curb the epidemic (4). However, treatment adherence and disengagement from care continue to be the system's most significant challenge (5). The benefits of ART can only be realized at both individual and population levels if patients are retained in care and adherent to the treatment (1).

Therefore, much of the emphasis on HIV research is now focused on the long-term challenge of patient engagement (6). In recent years, there has been an increased emphasis on coupling engagement within the HIV treatment cascade. This has created a framework process of sequential care engagement steps for patients– starting with HIV testing, linkage to care, retention in care, adherence to treatment, which finally results in viral suppression (7). However, to date, there is no universal definition of the meaning of patient engagement (8). In this paper, we will use the Higgins et al. definition which states patient engagement is “the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual in cooperation with a healthcare provider or institution for the purposes of maximizing outcomes or experiences of care” (9).

Reasons for disengagement from care have been researched extensively. Studies have found that there are several barriers at both the individual and system level, including associated

costs with treatment (such as monetary and time), competing priorities (such as work and family responsibilities), stigma and fear of disclosure, lack of social support, mental health and treatment fatigue (1, 10-13). Patients who are thought to have disengaged or have an unknown outcome are often categorized as "lost to follow-up" (LTFU) (10). Generally, LTFU patients are interpreted by clinical staff and researchers as being “out” of care, but recent literature suggests that there may be many who sought care at a new facility (10). This is known as "clinic switching," which, simply defined, is when a patient transfers care from one facility to another. Clinic switching can be facilitated through formal channels such as when a patient requests an official transfer letter or informal means by which a patient independently moved to a new facility without filing official transfer documentation, which is known as "silent transferring” (10).

Clinic switching has been an ongoing concern for healthcare systems as it wastes resources and creates misclassification, ultimately resulting in inaccurate data and, more importantly, poorer health outcomes for patients (14-18). Currently, clinics are not yet fully equipped to track patient movements from one facility to another, and some people deemed LTFU may actually be engaged in care at another facility (14). Health systems may as a result report an inflation of LTFU proportions. In addition, when a patient switches a clinic, a duplication of clinic resources must be completed for initial intake into the new program (17). Further resources may be consumed if the patient becomes ill during the time span between the last clinic visit at the original clinic—where ART was initiated— to the first visit to the new facility. By definition, clinic switching needs to be regarded as a public health problem as it fragments the continuation of care for patients, ultimately leading to impaired health outcomes for patients.

To gain better understanding of this challenge, we conducted a qualitative study exploring the reasons why patients clinic switch or "silent transfer", and its relationship to patient

engagement. The objectives of the study were to identify the driving factors that influence HIV-positive people to switch clinics, to understand the process of clinic switching, and to examine the factors that influence a person's move to a new clinic.

METHODS

Overview of Study Design

We conducted a qualitative study using semi-structured interviews in Gugulethu, a neighborhood outside of Cape Town, South Africa, from June-August 2019. Using a purposive and snowball sampling technique to identify and recruit participants, we conducted 19 semi-structured interviews that lasted, on average, 50 minutes. Transcripts were then analyzed using an inductive and deductive thematic analysis to identify and explore patterns of meaning across the interviews.

Study Setting

This study was conducted in Gugulethu, a former African township located 15km from Cape Town, South Africa. Residents of Gugulethu are a majority isiXhosa speaking and are predominantly of low socioeconomic status. It is estimated that the HIV prevalence rate in the Gugulethu community is around 27% (19). The vast majority of people seeking health services and ART use local public health services that are provided free of charge. However, many of these clinics are often overburdened and are low resourced (4). In Gugulethu, there are four primary HIV treatment clinics with at least ten more in the surrounding communities. Most clinics in the area used a paper-based management system of HIV/AIDS patients. Each patient visiting the clinic has a unique personal folder, which is comprised of personal and clinical information. At each visit, respective folders for the patients are retrieved, and entries are made by hand in the patients' files by either the administrative clerk or the nurse. Patient data is then typically entered electronically into database programs (15). Patients who have shown excellent maintenance of

treatment adherence were frequently allowed to join Adherence Clubs which are groups of patients who will receive group counseling and would be given a three-month supply of ART medications (20).

This study partnered with a community organization *Movement for Change and Social Justice (MCSJ)*, which is "an alliance of organizations aiming to improve the health and lives of people in Gugulethu and the surrounding areas" (21). Established in 2016, MCSJ is primarily focused on health issues, including access to and the quality of healthcare services and issues around the high rates of HIV, TB, and chronic diseases in the area (21). Members of MCSJ are considered community activists and are well known throughout Gugulethu, surrounding areas and in HIV care clinics (21). Three MCSJ members volunteered to assist with study recruitment and act as translators when needed during interviews.

Population and Recruitment

We enrolled a total of 19 study participants who are people living with HIV (PLWH), above the age of 18, and have clinic switched either formally or silently at least once since starting ART. We used a purposive sampling and a snowball technique to identify and recruit participants. MCSJ staff members presented an overview and the objectives of the study at the monthly MCSJ community meeting. Interested community members were encouraged to contact an MCSJ staff member for initial eligibility screening and to schedule an interview. In addition, known PLWH who have switched clinics were approached by MCSJ staff in the community and asked if they would be interested in participating in the research project. At the end of all interviews, the participants were asked by MCSJ staff if they knew anyone else who met eligibility requirements that might be interested in the study. MCSJ staff would then contact potential participants to assess interest in the study.

Semi-Structured interviews

In-depth, in-person, semi-structured interviews were performed by the first author and assisted by one of the three MCSJ staff members who volunteered to help with the study. Each staff member was trained in basic qualitative interviewing procedures and translation methods. Each participant was given a choice to conduct the interview in English or in isiXhosa, the local language, with the MCSJ staff member translating verbatim the English question being asked and the isiXhosa response. The interviews were audiotape-recorded after permission was obtained from participants (one participant declined to be audiotape-recorded, however, interview notes were included in the analysis). Each interview session was conducted in a private room at the MCSJ office or in a convenient place of the participant's choosing.

The interviews lasted an average of 50 minutes. The interview guide was created based on a literature review and *a priori* knowledge of the topic. The researcher also used cognitive interviewing testing with an HIV positive community member to test for understanding and wording of the interview questions. The interview guide focused on five domains; 1) overall patient experience receiving HIV care, 2) motivation and reasoning for switching clinics, 3) the steps to switching clinics, 4) the process of choosing a new clinic, and 5) the experience at the new clinic.

Data Analysis

All 19 interviews were transcribed, and 10% of transcripts were checked for accuracy. All transcription files were uploaded into NVivo software for qualitative data management to facilitate data analysis. The transcripts were analyzed using inductive and deductive thematic analysis to identify and explore patterns of meaning across the interviews. An initial thematic coding structure was developed based on the structured questions from the interview guide. The first author, using the coding structure independently, coded all of the transcripts, revising and adding to the scheme

until no new emergent codes were identified and there was a complete codebook. The full analysis team reviewed the initial codebook and thematic results, which resulted in additional queries, discussion and further refinement of thematic results.

In addition, the researchers used Symbolic Interactionism as the theoretical framework to guide analysis. Symbolic interactionism is based on the assumption that PLWH shape their illness and response to it based on their social interactions within society giving it meaning (22).

Ethics

This study is situated in a NIH funded R01 study called iALARM (IRB0001938, Co-PI's: Colvin and Lurie), which seeks to understand the HIV treatment cascade among men in Khayalitsha, South Africa. This study was approved by the IRBs at the University of Cape Town and Brown University. Written and verbal informed consent, administered in either English or in isiXhosa, was obtained from all participants before beginning data collection.

RESULTS

Of the 19 participants who were enrolled in the study ten were female, and nine were male. Participant characteristics are presented in Table 1. Participants had an average age of 41 years and had been diagnosed with HIV for an average of 14 years. Approximately a third (31.6%) of the participants were currently disengaged from care and were no longer attending a clinic. Seventeen of the participants had transferred clinics more than once, with participants on average transferring four times. 89.4% of the participants had also attempted to transfer silently at least once.

Although this study initially sought to explore the motivations of patients who engage in "clinic switching," our research culminated into a broader understanding and critique of how

researchers and clinicians have historically understood patient's engagement and retention in care. Instead of thinking of engagement in care in terms of the traditional linear cascade, participants often relayed their experience in the context of a "cycle" of engagement, using clinic switching, "silent transferring," or other tactics as a mechanism to maneuver within the system. We identified five salient themes that represent varying points in a patient's cycle of engagement of those participants who have experienced an episode of disengagement; 1) continued barriers to care, 2) internal and external stigma to be the "perfect patient" that led patients to fully disengage, 3) pull factors back into care, 4) patients mechanisms to navigate re-entry into care and finally 5) continued motivation to stay engaged in care.

Theme 1: Patients who have had successful long-term engagement in care can still experience barriers and struggle to maintain their engagement

Even though, on average, participants in this study have had an HIV positive diagnosis for fourteen years and have at some point in time been successfully engaged in care, many discussed a variety of external barriers that still interfere with maintaining their HIV care and engagement. This clearly illustrates that even well-adjusted, engaged patients can yet have unforeseen challenges that endanger their engagement status. As such, numerous participants indicated competing priorities that took precedence over receiving care or that disrupted their care routines. Frequently, fundamental needs, such as earning an income were seen as an opportunity that participants could not turn down. Either participants worked as migrant laborers and were unable to return home in time for clinic visits or they received unpredicted opportunity for informal work. Additionally, other life events such as family funerals or changes in family responsibility were also discussed.

> *"Sometimes haven't got support even in your homes, sometimes you haven't got support even in your family, and you don't work, there's no jobs, and you can't eat*

tablet without food, there's nothing that you can do about that but go get a job… not go to your date (clinical appointment).” (Male)

“I've got the family in Eastern Cape, so I go to do the funeral. And then we there, we found there's no elder people that can stay there in that house, so I must come later on to come in Cape Town. Not knowing I must come with a load of tablets, so I start to default.” (Male)

Furthermore, not having money for transportation costs to attend clinic appointments or the decision to save the money that would be used for transportation was a regular occurrence among participants.

“Because I was still taking the medication that side in Khayelitsha, so sometimes I don’t have (money for) transport…. (when I would find) transport fare, then when I goes there (to the clinic), they said, "No, your date has passed." Maybe, the date was last week, so they gave me another date. So you see now, that experience is very frustrating, because there's no doctor. Now the 20 Rand that I had, I rather save it for food maybe or save it for something for my child, rather than to just go and know that I might get medication, or I might not get it.” (Male)

Theme 2: Patients hoped to be seen as the “ideal patient” in the eyes of healthcare workers, which led to disengagement when this ideal could not be maintained

Often these barriers led to patients missing appointment dates or not perfectly adhering to medications. Participants would then return to the clinic at the time they could but were then often met by “unwelcoming” healthcare staff. Unanimously, participants reported instances of being shouted at or punished, both implicitly and explicitly, by healthcare workers. Public shouting was consistently used as a method to shame poor treatment adherence or clinical attendance. Often health workers disclosed confidential information such as a patient’s HIV status, STI status, or non-adherence publicly in the waiting rooms. This often made an already struggling patient disengage and leave the health system entirely.

“So when you miss a date, those doctors here in our location, they start to swearing you…shouting, swearing at you in front of other people. That is nothing. That thing make your dignity like this (foot stomps the ground and smooshes the floor).” (Male)

"I just left my ARVs, that's why I'm not taking my ARVs, because now I had to pull myself out from the system because of the way they (healthcare workers) treat me, I don't feel like a man, I'm nothing." (Male)

Others also reported being punished by healthcare workers using a variety of tactics. Common issues included long wait times, being taken out of adherence clubs, misplacing patient folders, and making patients come back another day after already being at the clinic all day.

"Nurses can be very rude. Nurses sometimes they can think they are God. They think they own you sometimes… They can belittle you very much, those people and punish you. Because they know everything is in their hands, you see? When you must receive treatment from them, whether you go fight with them, where you go out, you're going to come back again and they're going to treat you the same way they treat you." (Female)

"I would spend the whole day at the clinic and wake early. I would go and wait and wait and wait and I got nothing. I'll sit the whole day only to be shouted at to come back tomorrow. I come back tomorrow and same thing. They wouldn't give me my treatment. No man it was too much for me. I spent the whole week going up and down to the clinic. So, I decided I am just going to sit down (default)." (Female)

In many discussions patients described the feeling of wanting to live up to the ideals of the "perfect patient" both for themselves and to adhere to nurses' expectations. However, when a patient fails to perform their role of the "perfect patient" by missing appointments, forgetting medication or is seen as being unmotivated, they often exhibited thoughts and behaviors of internalized stigma. Frequently, citing feelings of shame, embarrassment, or how their experience engaging in care has differed from that of the "norm."

"Everybody was looking up at me, but now I felt right now I failed many people and I failed myself because of the treatment that the doctors and the nurses in the clinics... They will tell you that no, I was a great example… I was the one who was inspiring other people. Right now, but it's not like that. I feel now the system has failed me. And I don't feel South African. I don't feel like a South African because now the way they treat me when I go to the clinic." (Male)

"After I defaulted, I was afraid to go back there because I know all the nurses and the people, that staff who's there. They know I defaulted, so I didn't go back there because I was ashamed." (Male)

Theme 3: "It is the right time for me now": Patients reported varying pull factors that motivated them back into formal care

Among participants in this study, there was a range in the length of time spent out of care after an episode of disengagement. Some participants reported being out of care for a couple of months while others waited years to return to formal care in a clinic. There were a variety of pull factors that motivated a participant's readiness to return to care formally. A couple of participants, while trying to maintain their health, became ill with tuberculosis (TB), forcing them back into the health system. Others noted a deterioration in their health that was less serious but became enough of a concern to want to seek medical help.

> *"I go to the mirror to look myself, now I see the change. I see the change, I'm growing thin, all of those things. I've got a lot of things, breathing maybe heavy… I knew it was time (to return to care)."* (Male)

Others often relied on or were convinced to return to the clinic by family, social, or community support. Support systems that influenced participants to return to care varied from daily check-ins from friends and family, giving space for participants to talk about everyday struggles or giving a sense of camaraderie between friends or community groups. Family members also offered transportation or a place to stay when needed for the participant to get back on their feet.

> *""Are you fine? Is the medication right for you? Did you take it? Should I remind you by phone? Or what?" So you should at least disclose to one particular person, even if it's your partner or your family member or someone that you trust from the community. That will give you courage to go back and continue."* (Female)

> *I did tell my sister, I did tell her I don't want to go (back) to (clinic name), I'd rather die. But my sister said no… That I need to keep going."* (Male)

Nearly all participants reported the importance of self-management of one's health by taking a sense of responsibility for it. Regularly, participants shared the perception that if no one

else is going to look after their health, they must be the ones to do so. Generally, in these statements, participants showed qualities of self-agency and self-efficacy that led to the perceived capability of returning and remaining in care.

> *"So I told myself it is the right time for me now. To stop playing hiding seek. To stop hiding in the bush. Because it's my life. It's my life. I have to go, and I have to be responsible for my life."* (Female)

> *"You see? That is my medication. I must eat my medication because if I don't eat that, when I don't treat myself, who is going to treat myself? I treat myself so that I can be healthy."* (Male)

In all, there did not seem to be one specific pull factor that motivated patients back into care but a culmination of events and factors that lead to a patient's agency and self-efficacy to maintain their health and return to the clinic.

Theme 4: "So, I am going to make a plan now and I am going to make tricks… whereby I am going to be a new person again": Patients discussed multiple ways of maneuvering a health system to make it work for them

Participants discussed wanting to return back into care as "start(ing) fresh" or having a "do-over" to patient engagement. It was important for them to have their slate wiped clean and to disregard their previous experience within care. Although the participants in this study had varying ways of doing this, each found creative tactics to make the system work for them.

"Go back to start, you're going to start from there. From scratch." (Female)

Participants frequently reported wanting to escape the discrimination of being labeled as a "difficult patient" by healthcare workers in the clinic they attended previously and thus went to a brand-new clinic to restart their treatment. Therefore, for many to receive a fresh start as a "new patient" in a clinic, participants used informal silent transferring methods to attend a new clinic. Participants used a variety of tactics to return to care including using a fake name, a fake address or retesting to "find out" about their HIV status.

> *"I was (re)-tested in (clinic name). As a new patient. As a new person.... (I gave) them another address and another name."* (Female)

> *"I went and retested at a new clinic and didn't tell them of my status. I pretended that I was new and need help. I don't want to lie. I did give them a fake address that was in Gugulethu because I was scared, they would send me back to (clinic name)." (*Female)

> *"I have changed my names when I went to the clinic, they asked me for my ID but I told them "I don't have an ID." And the clinic say, "Okay. We'll assist you, but please, go and apply for ID." And then when I arrive, there's no more (participants name)."* (Male)

However, this trick apparently did not work for everyone as some were "caught" by a new computer system that used a patient's names, date of birth, and ID number to track a patient's history. Often participants would arrive at a new clinic and would be declined services because they did not have an official transfer letter. Patients were then instructed to go back to their original clinic to retrieve the documentation in order to attend their new clinic. While some participants were able to maneuver within the system to achieve this task successfully, there were a few left in limbo, feeling unable to receive care at any clinic. In the quote below, a participant described how a nurse discovered that she was silently transferring and then only returning to the same clinic six-month later to try to receive her treatment again.

> *"I went to (clinic name), she said to me, "No sis, I can't help you. Because on the system, it's written, you belong to (clinic name). So, you have to go back to (clinic name)." I stayed for six months without my treatment...I was running out of ideas so I thought I would try to go to (clinic name) again, but the same nurse saw me. "Sis, how many times must we tell you that you mustn't come back here. Sis, just go back to the (clinic name). Please. Just go. I'm busy. I'm very busy." You know, it's like that. Then I go, then I went out. Because I don't have a choice." (Female)*

Barriers to returning to their previous clinic include fear of repercussions from previous clinic staff or not being able to afford transport money back to their previous clinic. The woman who is quoted below was working as a migrant farmer when she began taking her medication. She

currently can't afford the transport money back to retrieve a proper transfer letter but claims no clinic in Cape Town will treat her without it. She has tested at seven different health clinics and mobile clinics trying to gain access back into treatment.

> *"You know, it is painful and sad in our communities, because when it comes to people that has default, they take it as if they don't care about themselves. Now in the case of the me I am willing to be on medication, but they are blocking me.... Where must I go? What must I do? Because (clinic name) doesn't want to take me. (Clinic name) also. So, what must I do? I really don't know... because I'm lost. I'm really lost. What must I do?"* (Female)

Participants also mentioned alternative tactics that they have employed to navigate their care. One tactic that was frequently used was by patients who had knowledge of the required transfer letter policy would often lie to healthcare workers about the reason for leaving. Six participants said it was easier to acquire a transfer letter if you lied and told a healthcare worker that you were leaving Cape Town and going to the Eastern Cape or to another province.

> *"So I decide to ask the transfer to go to another clinic. They asked me, "Where are you going now?" I said, "I'm going to Eastern Cape. I didn't tell them I am going to Khayelitsha... They would shout at me if they knew the truth"* (Female)

Three more participants also noted the best way of procuring a transfer letter was going straight to the doctors instead of asking nurses. Often, participants remarked that doctors were usually more understanding and helpful.

> *"So doctors they don't have a problem. There is only sisters(nurses) they have a problem. If you want to transfer, you must go to the doctor new to the system because if you go to the sister, they said you must wait… But if you go to the doctor, I need the transfer I'm going now… They want you to take your tablets."* (Female)

Others tried to limit their time at the clinic by sending relatives or friends to retrieve their medication instead of going themselves. This way, participants were able to receive their medicines while still being able to manage other priorities such as work or other important events.

> *"Sometimes I send this boy to the clinic, I say "go and fetch my meds at (clinic name)." That way I when I feel fine and I don't need to see the doctor I just need my meds I can stay home and take care of my mother and clean the house."* (Male)

One participant is even able to use an online community via Facebook group to reach out to strangers who are also HIV positive to bring her medication in times of emergency.

> *"Sometimes I send somebody. Now I connect with people on Facebook. "Guys, please." I even got two cards, two clinic cards. The one I left there. "Just check on my cards. Take my card and go to the clinic and fetch my treatment. If you are coming to Cape Town, please bring my treatment." You see? For me to go there, it's very difficult so I must sometimes reach out"* (Female)

Theme 5: "I am good here. There is a lot of care so I will stay put": Patients who felt as if they were cared for and respected by healthcare workers often remain at their clinic and reported longer engagement

In total, seven participants said they were happy with their current clinical care and engagement and had no future plans in changing clinics. In general, participants who were more content in their clinic often felt that they were receiving better care than they have had in previous clinics.

> *"There is a lot of care here. They are professionals."* (Male)

Participants regularly related good care with positive relationships between healthcare workers, mentioning provider-patient communication, trust, confidentiality, and understanding. It was important for participants to feel supported by healthcare workers and had time to listen to patient concerns or questions.

> *"They know how to talk to each other; they know how to talk to me. They don't shout. They believe what I say."* (Female)

> *"So we can help support you. We are here. If you've got a problem, just talk. And say what is the problem. And we'll see what we can do. So that's the relationship. It's a two-way street. To help each other."* (Male)

DISCUSSION

Increasingly, clinic switching and silent transferring has been noted as a growing concern within the existing literature that tracks PLWH outcomes (14-18). These in-depth interviews provide a voice and context of PLWH personal motivation and experience for clinic switching. We identified five separate but interconnected themes that relate to patients' engagement and movement within the HIV health system.

From the success of ARVs, life expectancy continues to improve, creating an emerging population of PLWH that has been in care for over ten years (23). This study was unique in that the participants who were recruited have had an HIV diagnosis on average for 14 years. Our findings suggest that long-term engagement in care can be just as challenging for patients as it is to get them to first enter the system. Many of these participants reported having no formal employment and most did not have a stable income. Eshun-Wilson et al. suggest that poverty creates instability for patients often making engagement fragile (13). Participants in this study reported missing appointments or poor treatment adherence due to competing priorities, changes in family responsibilities, or lack of transportation fare. All of these barriers have been discussed in pre-existing literature, but they have not been discussed as a continued barrier to care in the context of long-term engagement. Therefore, insecurity at any time can change engagement status for a patient.

Following missed appointments, most participants who returned to the clinic would face disrespectful healthcare workers and often would be punished for not adhering to clinical guidelines. As a result, many participants came to associate care mentioning scoldings, punishments and being labeled as a "difficult patient." The expectation set by healthcare workers that PLWH should strive to be "good patients" contributed to the patient's internalized stigma. Therefore, many participants attached a moral framework to engagement, often expressing feelings

of shame, embarrassment, and frustration after being scolded or punished by healthcare workers (8). In addition, this mindset leads many participants to believe in an all or nothing approach when it comes to engagement, that they either have to have perfect adherence or they should stop coming to the clinic all together. These findings are consistent from the study by Layer et al., that stated, "abusive treatment by service providers following an absence was the main cause of disengagement and reluctance to return to care" (24).

Prior to reengagement, participants reported multiple different pull factors that brought them back into care. Most often, support systems stemmed from family, friends, or the community were noted. Participants also came to recognize their health and their HIV status as their own responsibility and felt a strong desire to self-maintain their health status.

All of the study participants had experienced an episode of clinic switching. Participants primarily expressed how clinic switching was a method to return back into care as a "new patient." By switching clinics, participants felt as if they were granted a fresh start and were given a redo at patient engagement. Clinic switching was just one method that was used by patients to navigate back into the health system.

In this qualitative study, we explored methods and motivations of clinic switching among South Africans who have been living with HIV for more than a decade. Yet, we really uncovered a much more comprehensive and explanatory model of HIV patient engagement broadly. Historically, researchers and clinicians have understood HIV care in the context of a linear cascade model that seeks to describe the relationship and movements of the patients within the health system. Starting first with HIV testing, linkage to care, retention in care, adherence to treatment, and finally viral suppression, this model explains patient's engagement as unidirectional and indicates a streamlined progression of steps (7, 25). We argue, however, that this traditional

cascade model is incomplete as it often fails to acknowledge the social realities of those who do not fall on this so-called linear line and the dynamic nature of retention. This study found that patient engagement is often fluid as PLWH "cycle" in and out of care multiple times during their lifetimes using clinic switching and other methods to maneuver and navigate a complicated, and sometimes punitive health care system.

Recommendations

These findings highlighted critical points along a cycle of patient engagement that can potentially help to inform new clinical policies and intervention programs. To begin with, we must encourage clinics to adopt policies that supplement the traditional linear cascade model by understanding how engagement is nuanced, and patients tend to experience cycles. We echo the suggestion of Koester et al. adoption of patient-centered engagement definitions (8). This would allow for patients and healthcare workers to collaborate together to define the specific parameter of care engagement for each individual (8). We hope that this will continue to build realistic engagement expectations for each patient and expand upon patient-provider communication. Furthermore, clinics should steer away from promoting perfect adherence, because lack of perfect adherence is often a reason patient get scolded. This will hopefully encourage patients that treatment adherence does not have to be an all or nothing approach but instead urges patients who are struggling to continue treatment to seek help at their clinic.

In addition to clinics changing engagement and adherence policies, new interventions should be created designed to educate healthcare workers about the complexities of a patient's cycle of engagement. Clinics and healthcare workers need to create a clinical environment where patients feel welcome, cared for, supported and understood. At the moment, there is no clear solution to how to end poverty or eliminate all of the barriers that patients frequently report. Still,

we can change how clinics and healthcare workers respond to patients who are struggling and create a system that does not punish them but instead supports them. Interventions should continue to address how to best educate and change healthcare workers' communication techniques, body language, and understanding of patients by giving healthcare workers newfound skills such as motivational interviewing (26).

Lastly, we recommend refining policies to ensure that patients can quickly and smoothly access care in multiple locations within and beyond a province. This can be accomplished by integrating health information systems more effectively where patient information can be accessed across clinical sites. After silently transferring, some participants in this study became stuck and unable to receive care at a clinic. Because of this, we suggest the adoption of "health passports" which would enable patients to receive care at varying facilities. At the bare minimum, official transfer letters should be redesigned to make the process more accessible and easily understood by patients, so that these letters become a facilitator, not a barrier to re-engagement in care. Patients should be educated on what a transfer letter is and how to acquire one during their first counseling session upon being linked to care. In order to ensure success regarding these transfer letters, clinics should work to create a new position whose designated job is to implement and manage the transfer letter system. This will create a neutral third party for the patient to approach regarding transferring. By removing the need for a patient to acquire a transfer letter from his/her healthcare worker, patients will more easily be able to transfer clinics should they need to. We hope that this creates a more impartial environment where patients feel more comfortable obtaining a transfer letter.

Strengths and Weakness

This study did not set out to focus directly on a patient cycle of engagement. Instead, themes developed within this conceptual domain after an in-depth analysis of the given data. Therefore, there may be several other theoretical frameworks that describe the narrative of engagement for a patient. However, the interview guide was not designed to investigate experiences of barriers to care, disengagement, or maintenance of health. Yet all of the participants in this study spontaneously discussed these topics with the interviewer.

Additionally, some of the participants who were recruited for this study were either involved with or were closely associated with MCSJ. As such, it is possible that these participants may differ in some way to other people's HIV positive clinic switching experiences. However, the authors believe that if anything, their involvement or relationship to MCSJ should make these participants more resilient and less likely to have disengaged as they have a more robust social support network.

To date, there has been very little literature or qualitative studies that have examined clinic switching. To our knowledge, this is the first qualitative study in sub-Saharan Africa (SSA) to explore PLWH motivations and experiences for clinic switching. However, as this paper only presents the perspectives of the patients, future research should also include the perspectives of healthcare workers. This research should consist of studies that examine the knowledge, perceptions, attitudes, and behaviors towards patients who have clinic switched and those who have disengaged. In addition, this paper is a call for future research to continue to investigate the conceptual framework of a patients' cycle of engagement.

CONCLUSION

The results of this study highlighted the lived experiences of patients who have switched clinics. Their stories revealed the nuances of a patient cycle of engagement. As efforts continue to focus on long term engagement, researchers, clinicians and policymakers need to continue to take note and seek to understand the lived experiences of patients. Every day, patients make decisions about whether or not to remain in care and often weigh their own pros and cons. Clinics need to create an environment that is welcoming to new patients, returning patients, and struggling patients.

TABLE

Table 1: Characteristics of Study Population

Characteristics	Percentage (count)
Gender	
Male	47.4% (9)
Female	52.6% (10)
Age	41 years (mean)
Ethnicity	
Xhosa	100% (19)
Marriage Status	
Single	57.9% (11)
Married	42.1% (8)
Employment Status	
Formal Employment	21.1% (4)
In-Formal Employment	36.8% (7)
Unemployed	42.1% (8)
Number of Years Since Diagnoses	14 years (mean)
Current Clinical Engagement Status	
Engaged and Retained in care	68.4% (13)
Disengaged from care	31.6% (6)
Clinic Switched More Than Once	89.5% (17)
Number of Clinic Switches	4.2 (mean)
Participants Who Attempted to Silent Transfer	84.2% (16)

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