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Community perspectives of South African adolescents' experiences seeking treatment at local HIV clinics and how such clinics may influence engagement in the HIV treatment cascade: A qualitative study

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Abstract

Despite having the largest antiretroviral treatment (ART) program in the world, only 14% of South African adolescents living with HIV (ALWH) are on ART. The purpose of this study was to identify aspects of the clinic environment that either improve or inhibit ALWH's ability to engage in HIV care. We conducted fifty-nine semi-structured, in-depth interviews with ALWH (n=20; 13-19 years of age), their caregivers (n=19), and local stakeholders (n=20) in Cape Town, South Africa. Data were coded and analyzed using inductive and deductive approaches to content analyses. Codes were grouped into positive and negative aspects of the HIV clinic environment, and into suggestions on how clinic practices could be improved to facilitate ALWH treatment retention and ART adherence. Positive clinic factors included: community co-location; familiarity with clinic staff; and adolescent only/adolescent-friendly clinic spaces. Negative clinic factors included: clinic visit frequency; overcrowding and long wait times; discrimination and stigma; lack of confidentiality; inflexible appointment-scheduling; and staff attitudes. ALWHs' clinic experiences affect their ability to remain in care and adhere to their treatment regimens. These findings support a call for innovative approaches that improve ALWH's clinic experiences and support them as they progress along the HIV treatment cascade.

Keywords

HIV; clinic experiences; adolescents; South Africa

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INTRODUCTION

Of the 26 million people living with HIV/AIDS in sub-Saharan Africa, 30% reside in South Africa (Statistics South Africa, 2015). Among these, approximately 870,000 are adolescents (15–24 years) (Zanoni, Archary, Buchan, Katz, & Haberer, 2016). Research has shown that, among adolescents living with HIV (ALWH), only 14% are on antiretroviral therapy (ART) and 10% are virally suppressed (Zanoni et al., 2016), leading to high levels of HIV-related morbidity and mortality. As such, there is an urgent need to identify factors that contribute to poor retention in HIV care (i.e., absence of at least one visit in six months or < two visits in 12 months) and low rates of ART adherence among South African ALWH (Dahourou et al., 2017; Inzaule, Hamers, Kityo, Rinke de Wit, & Roura, 2016; Kung et al., 2016; Lee et al., 2016). The clinic setting may be one such factor (MacPherson et al., 2015; Nkala et al., 2015; Tanner et al., 2014; Williams, Renju, Ghilardi, & Wringe, 2017; Wolf et al., 2014).

HIV clinics in under-resourced communities often suffer from physician shortages (Burmen, Owuor, & Mitei, 2017), inefficient intake and scheduling systems (Maughan-Brown et al., 2018), and poor provider communication (Bernays, Paparini, Gibb, & Seeley, 2016) and staff attitudes (Maughan-Brown et al., 2018; Rawat, Uebel, Moore, Cingl, & Yassi, 2018), all of which may reduce adolescent treatment retention and adherence. This study sought to identify clinic-related facilitators and barriers to treatment retention and adherence among ALWH in Cape Town, South Africa.

METHODS

Participants and procedures

Eligibility criteria for ALWH, their caregivers, and community stakeholders are outlined in Table 1. We recruited ALWH and/or their caregivers from the waiting room at a local HIV clinic in Cape Town and stakeholders from local organizations serving ALWH. Interviews were individual, semi-structured and conducted in-person between May and September 2016 in either English or isiXhosa.

We developed an interview guide that consisted of questions aimed at assessing socio-structural determinants of adolescent retention in HIV care and ART adherence (see Table 2). Interviewing continued until a full range of responses was obtained and additional interviews did not lead to new insights. Participants received a cash incentive of 80 Rand ($8 USD). The institutional review boards at the Medical University of South Carolina, the University of Cape Town, and the Western Cape approved this study. All participants gave written informed consent or assent.

Interviews were audio-recorded, transcribed, translated, and back-translated. We used inductive and deductive approaches to thematic analysis to identify, analyze, and report themes (Braun & Clarke, 2006). Discrepancies among coders were resolved through in-depth team discussions, with agreement between two of three coders required. The final set of codes was entered into Atlas.ti 7 for analysis.

RESULTS

Fifty-nine adolescents, caregivers, and stakeholders participated in this study (Table 3). We identified three clinic-related facilitators and six barriers to treatment retention and adherence among ALWH (Table 4).

Facilitators.

HIV counseling and education.—Stakeholders and caregivers suggested that HIV counseling and education provided ALWH with an opportunity to process their diagnosis, better understand the impact of HIV on their lives, and correct HIV-related myths, leading to greater acceptance of one's HIV status. Participants, including ALWH, suggested that a lack of education about HIV was a serious concern within their communities.

Adolescent-friendly practices.—The availability of adolescent-focused or adolescent-friendly practices was the second most identified positive clinic facilitator. Programs described as 'adolescent-friendly' included those in which there was: 1) an adolescent-only clinic or certain days devoted to adolescent care; 2) a dedicated youth space; and 3) healthcare integration.

Co-located community HIV clinics.—Some stakeholders and caregivers suggested that being served by clinic staff from their communities meant that the staff would be more familiar with the culture of the community, enabling them to be more responsive to patients' needs and challenges. Moreover, co-located clinics were described as convenient and cost-effective.

Barriers.

Long waiting times and overcrowding.—All participants indicated that HIV clinics in their communities were frequently short-staffed. It was common for ALWH to arrive early in the morning for clinic appointments and not be seen until late in the afternoon.

Singling out.—Stakeholders and caregivers described clinic protocols separating those receiving HIV-related services from others using a color-coding system as stigmatizing and harmful. Stakeholders reported that ALWH believed that such protocols increased the likelihood of involuntary disclosure of their HIV status to patients and staff at other clinics.

Lack of sensitivity and/or compassion.—Stakeholders reported that some nurses lacked soft skills when interacting with patients and often behaved in an authoritarian manner. Some participants suggested that even healthcare providers held negative beliefs about people living with HIV and associated this with poorer healthcare quality and ALWH attrition from HIV care.

School absences.—ALWH, particularly those with unsuppressed viremia, experience frequent school absences due to mandatory clinic appointments during school hours, which may occur up to six times annually. Some participants found that the absences led school personnel and students to speculate about the youth's HIV status.

Inflexible appointment scheduling.—Participants suggested that inflexible scheduling may lead to treatment default if ALWH were unable to attend appointments that required them to meet with their provider. Missed appointments and late arrivals often forced ALWH to wait weeks before they are able to meet with the provider for a mandatory in-person visit.

Concerns about confidentiality.—Lack of confidentiality at the clinic was a major concern among participants, as several suspected that both staff and other patients disclosed the HIV statuses of patients seen at the HIV clinic who live in their communities.

DISCUSSION

This study identified clinic-related facilitators and barriers to retention in HIV care and ART adherence among South African ALWH. Clinic-related facilitators included HIV counseling and education, adolescent-friendly practices, and co-located HIV clinics. Participants suggested that HIV counseling and education that places emphasis on educating ALWH, as well as their caregivers, on how ART impacts their bodies may lead to greater HIV acceptance and better outcomes among ALWH (World Health Organization, 2013; Roy et al., 2016). Relatedly, adolescent-friendly practices within HIV clinics may improve the clinic environment for ALWH and encourage engagement in other clinical services key to reducing HIV transmission, including sexual and reproductive health services (Mendelsohn et al., 2018). While co-located HIV clinics were viewed positively by participating adults, ALWH expressed concerns about the stigma associated with being recognized at the HIV clinic (Azia, Mukumbang, & Van Wyk, 2016; Bond et al., 2019; Maskew et al., 2016). Integrated healthcare models may alleviate such concerns, as they support healthcare continuity by enabling ALWH to receive multiple services within the same clinic and eliminates the stigma associated with being treated at a HIV specialty clinic.

We identified six separate, but interrelated themes characterizing ALWHs' barriers to treatment retention and adherence. Concerns regarding long waiting times and overcrowding, and school absences, may be due to the fact that HIV clinics in South Africa are chronically understaffed. Relatedly, participants identified appointment scheduling as a retention-related barrier. ALWH reported that school-related events, such as exams, may cause them to miss their regularly scheduled appointment. In such cases, rescheduling can be challenging. Such concerns are not unique to this study, and several clinics are actively exploring solutions to this issue (IAS, UNICEF, & WHO, 2018; Nachega et al., 2016). One approach includes the use of adherence clubs, or group-based models of care run predominantly by non-clinical staff where patients are able to receive their ART, as well as other healthcare-related support, without visiting a HIV clinic (Grimsrud, Sharp, Kalombo, Bekker, & Myer, 2015). Though widely used with adults living with HIV, the use of adherence clubs for ALWH has not been widely implemented or studied (IAS et al., 2018; Zanoni, Sibaya, Cairns, Lammert, & Haberer, 2017).

Singling out HIV patients, lack of sensitivity or compassion, and lack of confidentiality were also identified as clinic-related barriers to treatment retention and adherence. Such factors may be addressed if HIV services were adolescent-friendly, which requires not only changes in individual attitudes, but also a commitment to ongoing staff training emphasizing the

importance of patient-centered care. Such changes may require a commitment of financial resources and more importantly, change in organizational culture and clinic policy.

This study is not without limitations. Our study focused only on participants in Cape Town and most ALWH attended a single clinic. This, along with our small sample size and convenient sampling method, reduces the generalizability of this study. However, our findings are consistent with those across the country (e.g., Bond et al., 2019). Despite these limitations, this study contributes to our understanding of clinic-related factors associated with retaining South African ALWH in HIV care. While our findings suggest that South African ALWH face challenges that are similar to those of adults living with HIV, the challenges facing ALWH are compounded by having less agency with regard to healthcare decision-making. Effective triage models may ensure that those with the greatest needs receive crucial care and attention. This, and similar studies, may assist researchers in developing targeted intervention strategies that lead to positive outcomes among ALWH.

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Table 1.

Eligibility criteria for participants by source

	ALWH	Caregivers	Stakeholders
Age	13-19 years	21+ years	21+ years
Legal guardian or primary caregiver for participating youth	--	Yes	--
Ability to commit up to two hours for interview	Yes	Yes	Yes
Resided in the study community	Yes	Yes	No
Knowledgeable of issues affecting ALWHs' treatment retention and adherence	--	--	Yes
Enroll in study with eligible caregiver	Yes	--	--

Table 2.

Selected questions from the semi-structured interview guide by source

Stakeholders	Do you think young people in this community get HIV treatment? Why or Why not?
	What makes it difficult for them to link to care?
	What helps them to remain in treatment?
	What makes it difficult for them to remain on ART after starting a regimen?
	From your experiences, what do you think would be the best way to help HIV positive youth remain in care?
Caregivers	Is your child currently in treatment?
	What has helped your child to remain in treatment?
	What makes it difficult for your child to be in treatment?
	Tell me about your child's treatment?
	Where does your child go?
	How does your child get there?
	How frequently does your child receive treatment?
	How long does your child have to spend at a clinic visit?
	Are there barriers for your child getting to your appointments?
	What medications are your child taking?
	How do the medications make your child feel?
	How has medication helped your child?
	What barriers does your child experience with getting treatment?
	What could help reduce these barriers?
	Does your child have challenges taking pills every day?
	What are the challenges?
	What are things that help your child to take her/his medication regularly?
Adolescents	Are you currently in treatment?
	If yes,
	When did you begin treatment?
	Why did you decide to get treatment?
	Have you ever defaulted? If so, why?
	What has helped you to remain in treatment?
	Generally, what makes it difficult for you to be in treatment?
	What could be done to improve HIV treatment for you?
	Tell me about your treatment?
	Where do you go?
	How do you get there?
	How long do you spend at each visit?
	Are there barriers to getting to your appointments?
	What are the barriers?
	What could help address those barriers?
	How could your HIV care/clinic experience be improved?

Table 3.

Demographic characteristics of the participants (n=59)

	ALWH (n=20)	Caregivers (n=19)	Stakeholders (n=20)
Age, years			
Range	13-18	26-64	23-64
Mean (SD)	15.3 (1.4)	41.8 (10.4)	35.4 (10.6)
Gender			
Female	14	19	11
Male	6	-	9
Highest level of education *			
Primary school	7	2	-
High school	9	17	-
College	1	-	-
University	1	-	-
Ethnicity			
African	20	19	19
White	-	-	1
Residential area			
Gugulethu	16	14	10
Khayelitsha	1	1	1
Masiphumelele	-	-	4
Other	3	4	5
Marital status			
Cohabiting	-	1	3
Married	-	6	7
Partnered	-	1	2
Single	-	6	7
Widowed	-	4	1
Employed			
Yes	1	7	20
No	19	12	-
Length of employment			
Less than 1 year	1	1	6
1 year to 5 years	-	3	3
6 years to 10 years	-	3	5
11 years to 20 years	-	-	6

Note: * indicates that all participants did not complete this item. Stakeholders were not asked to indicate their level of education. All ALWH were single.

Table 4.

Overview of the participants' (n=59) description of positive and negative experiences at the clinic

POSITIVE EXPERIENCES AT THE CLINIC	
Themes	**Illustrative Quotations**
HIV counselling and education	*"…some people still need to be told about how HIV is and how dangerous it is if you're not taking your treatment. [Clinic A] will start by counselling you which is important to some people, being mentally counselled and to come to a state that, 'yes, I am accepting what I have [HIV] and [I'm] willing to move [forward].' These [clinics] that I have described give that platform for being counselled and finding peace, and continuing with your life and getting your treatment" (Stakeholder, 47-year old female)*
	"… I used to attend a [antiretroviral] clinic at [Clinic A]. In that clinic, there is a television and a video machine. That video machine is played every day of the clinic. Videos that are played there are teaching you guys about HIV/AIDS… where it comes from, the treatment…everything about HIV/AIDS and then there are days whereby you can ask questions. You can ask questions any day… And then maybe two hours in the morning after having played those videos and discussing things because everyone comes up with a point, a fact or whatever. After that time only then the TV will be played. So I think these… people [at Clinic B] are not educated enough about HIV/AIDS. The only time that I got education about HIV/AIDS was when I transferred my grandchildren from [Clinic A to [Clinic B]. So, we had to go for classes for six weeks… That was the only time. Since then, I have never heard anything being said about HIV/AIDS" (Caregiver, 61-year-old female)
Adolescent-friendly practices	*"For youth, we have, I think, a better program… they have a specific day where they come depending on the age group. We have specific clinicians seeing them. It's that day when they come, they've got the priority and they are often large. [On that day], they come as a group. They have group sessions just to have fun.* *Depending on the age group, the younger ones will be coloring… in the books while they are waiting for medication. They don't go to the pharmacy. So this is called the 5-star treatment where the counsellor goes and [picks up the] medication for them and brings it to them here [in the youth space]. And in the meantime, while they are waiting, they have fun or they have large discussions depending on the age group" (Stakeholder, 42-year-old female)*
	"…we try to make it as pleasant an experience as possible. So, the children get sandwiches and there is a room with a pool table and a TV and some books and crayons and things, you know? So, it's – you know, and it's often the children will – you know, often after their appointments are finished, they stay and hang out for the day here… We try to make it a youth-friendly place" (Stakeholder, 34-year-old female)
Co-located community HIV clinics	*"… I feel free here. People know me and I know them. I know the counsellors here and they know me even before I looked like this [healthy]. So, I feel free this side because I know everyone from the counsellors, [to the] nurses and doctors. You feel free. So, if I were to go to [Township A clinic], I wouldn't even know where to go first. But I'm still here and I feel free and fine in [Township B clinic]" (Caregiver, 33-year-old female)*
	"It's nearby. The people working here are more or less from the same area so you also get to be served by people, who, more or less, understand you… " (Caregiver, 61-year-old female)
NEGATIVE EXPERIENCES AT THE CLINIC	
Themes	**Illustrative Quotations**
Long waiting times and overcrowding	*"The whole day. [Laughing] Um… I would say… Maybe it's 5-6 hours" (ALWH, 18-year-old male)*
	"A long time. Maybe I'll leave home at 7(am) then come back at around 1 or 2(pm)" (ALWH, 13-year-old female)
	"Uhm, what they can improve is taking their time because for some of us, it's irritating sitting in the same place doing nothing. So, if they can do things quickly maybe we can leave the clinic early" (ALWH, 15-year-old female)
Singling out	*"Challenges, firstly I would say are the cards. For example, in the clinic, you'll find that people with HIV have different cards than other people, other patients. You find that we have _____cards. There is a ____ [color of HIV clinic folder] one and a _____ [color of a different clinic's folder] one. Thus, if you have a ____ [color] card, it's obvious to anyone that you will go to the other side. And then you find out that that is where people are found out that they are HIV without their actual disclosure. And you'll find that a person was not ready to disclose that they are HIV, but the person discloses because of the [color of the] card" (Stakeholder, 40-year-old female)*
	"Another thing that I think makes people scared of the clinic is this distinction [made by the color of the folders] of this clinic here; that for people who are positive, it's [a certain color]. It would seem better if their folders where the same, you understand, as others that have other illnesses. Now one is carrying a folder that is _____ [color of HIV clinic folder], another has a ____ [color of other clinic folder] one. It's already known that the [name of the color] one is for [the HIV clinic]. I'm making an example, you understand? That's what I hear when I am listening to patients in the clinic" (Caregiver, 48-year-old female)
Lack of sensitivity and/or compassion	*"…if you don't come on [your scheduled appointment] day [and pick up your] treatment, you become scared. I don't know what's scary because no one has ever been beaten at the clinic, but you are shouted at because you are a defaulter. So, [some are] scared to come and get treatment [at the clinic]" (Stakeholder, 47-year-old female)*
	"…it's the nurses' attitudes that people are always complaining about. People say they are treated badly and are afraid to go back to the clinic [because] a nurse will shout at them in front of people and not give them the confidentiality that they need" (Stakeholder, 23-year-old male)

POSITIVE EXPERIENCES AT THE CLINIC	
Themes	**Illustrative Quotations**
School absences	*"What is difficult is that there are a lot of tablets and you have to take them twice; you have to go to the appointment, which he [her child] has to go to after two months. Then, they tell him to come back every three weeks for the doctors to do their testing. So, this upset him because he was missing school during the times he had to be in these appointments. He used to say people used to ask him, "Where are you going? Why are you always out on Tuesdays?" and Tuesdays are the days for his appointments" (Caregiver, 33-year-old female)*
	"That's what disturbs me, the time. Because he is a schoolchild and even worse that he has started treatment this year, even at school he is lagging behind because most of the time when he comes [to the clinic], he'll be there the entire day and can't go back to school" (Caregiver, 44-year-old female)
Inflexible appointment-scheduling	*"So, adults go to clinics early in the morning and that is the time a lot of people are in the clinic and that is the time they don't want to go get treatment, because in the afternoon adults are told that they should have woken up early and are being shouted by the nurses, "We told you to wake up! You're not getting treatment." So that's where the system ruins us, in the afternoon we can go check this and you will find only a few people, but in the morning, it was filled with people this side" (Stakeholder, 28-year-old male)*
	"…you know if you miss your appointment then everything gets messed up and it takes longer to get back to normal. So, we try to keep up with our appointments so that we keep everything in order with our treatment. You know, when you run out of tablets, it messes things up because when you go to the clinic, they only attend to those that have appointments during that time and there would be long queues" (Caregiver, 33-year-old female)
Concerns about confidentiality	*"They are not treated with dignity and there is no confidentiality. It's either this reception or counsellor is in your community that's gonna talk about you or your daughter saying, 'she was there getting whatever.' So, there is not that level of trust within, yeah" (Stakeholder, 28-year-old male)*
	"…they are afraid of the lack of confidentiality. They say that their information comes out of the clinics" (Stakeholder, 47-year-old-female)
	"… [If you] go to the Day Hospital, [people think], "Oh, HIV patient, HIV patient, HIV patient." … I kept on thinking, "What will everybody say or [is] everybody gossiping about me?" So, thinking about all those things makes it difficult for people to come here" (ALWH, 18-year-old male)