



The first six months on antiretroviral therapy for HIV in South Africa: why do clients disengage from care?

BACKGROUND

- ◆ Within the first six months of starting or re-starting antiretroviral therapy (ART) for HIV, approximately **30% of HIV-positive individuals disengage from HIV treatment** or interrupt treatment for more than a month at a time.
- ◆ Most existing evidence about disengagement ART pertains to long-term outcomes, not the early treatment period (first 6 months).
- ◆ Research is needed to **drivers of disengagement during the early treatment period** so that client-centred interventions can be developed.

METHODS

- ◆ We enrolled a sequential sample of adults presenting for ART initiation or re-initiation or on ART for less than 6 months in Mpumalanga, KwaZulu-Natal, and Gauteng provinces from 7 September 2022 to 30 June 2023.
- ◆ After consent, study interviewers administered a **survey** with questions about demographic characteristics and socio-economic status, HIV treatment history, current HIV care and treatment experience, other healthcare, and preferences and expectations for treatment delivery.
- ◆ We collected **medical record data from Tier.Net**, the National Health Laboratory Services database, and study site paper records and registers.
- ◆ Approximately 12 months after study enrollment, a subset of participants were invited to **focus group discussions** to further describe their experiences in the early treatment period.
- ◆ Study outcomes included treatment retention and viral suppression at 6 months, predictors of retention and suppression, and emergent themes to qualitatively explain outcomes at the individual, interpersonal, community, and societal levels.

QUANTITATIVE SURVEY FINDINGS

- ◆ We enrolled 1,098 participants in the survey; 1,049 (95%) were linked to their clinic records.
- ◆ More than half (53%) reported that they would find it difficult to obtain R100 for a health emergency if needed.
- ◆ **24% had a baseline CD4 count below 200 cells/mm³** (advanced HIV disease).
- ◆ Participants' patterns of engagement were ascertained through Tier.Net data (Table 1):
 - ◆ **73% were continuously engaged in care** for the first 6 months (no interruptions >28 days) ;
 - ◆ 14% had 1 or more interruptions >28 days but returned by 6 months;
 - ◆ 9% disengaged or died in the first 6 months (Table 1).
- ◆ Two thirds of the sample had viral load test results documented:
 - ◆ **71% of these were virally suppressed** (<50 copies), 21% had low-level viremia (50-1000 copies), and 8% were unsuppressed (Table 1).

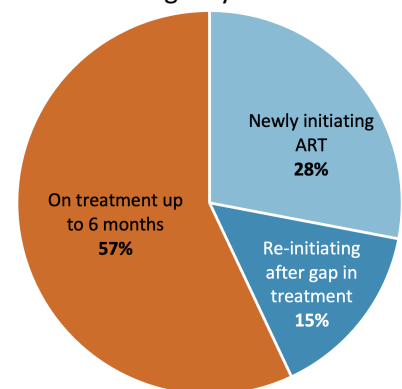


Figure 1: Time on ART at study enrollment

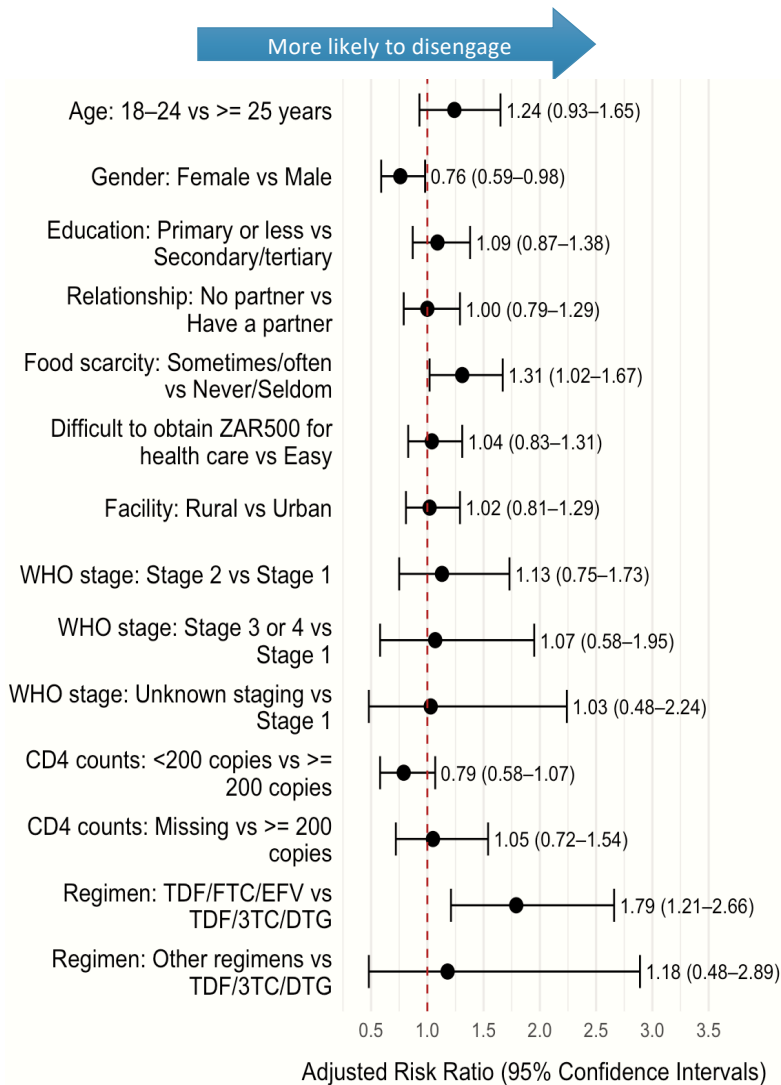
TABLE 1. VIRAL LOAD SUPPRESSION AT 6 MONTHS AFTER INITIATION, BY PATTERN OF ENGAGEMENT

Outcome in ETP ⁺	N	Continuous engagement [*]	Cyclical engagement ^{**}	Disengaged from care during the ETP ⁺	Documented transfer to new clinic	Died
Full sample (N) (row %)	1,049 (100%)	770 (73%)	142 (14%)	88 (9%)	45 (4%)	4 (0.5%)
No VL test documented	344 (33%)	169 (22%)	44 (31%)	87 (99%)	40 (89%)	4 (100%)
VL test documented	705 (67%)	601 (78%)	98 (69%)	1 (1%)	5 (11%)	-
If VL test documented,						
<50 copies/mL	498 (71%)	432 (72%)	64 (65%)	-	2 (40%)	-
50-1000 copies/mL	149 (21%)	130 (22%)	15 (15%)	1 (100%)	3 (60%)	-
>1000 copies/mL	58 (8%)	39 (6%)	19 (19%)	-	-	-

⁺Early Treatment Period defined as the first 6 months after initiation or re-initiation; ^{*}Continuous engagement defined as no interruptions >28 days during first 6 months;

^{**}Cyclical engagement defined as ≥1 interruption >28 days but returned by 6 months after initiation

FIGURE 1. PREDICTORS OF DISENGAGEMENT DURING THE FIRST SIX MONTHS ON ART TREATMENT

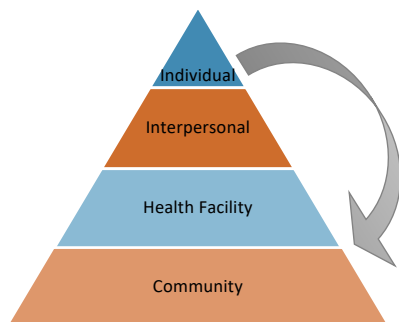


*Adjusted for age, gender, baseline CD4 count, and ART status at enrollment

- ◆ The clearest predictors of disengagement within the first six months were:
 - ◆ An ARV regimen containing efavirenz
 - ◆ Food scarcity at home
 - ◆ Male sex
 - ◆ Younger age (less than 25)
- ◆ Individuals who initiated treatment with CD4 counts **below 200 cells/mm³ were slightly more likely to remain continuously in care** than were those with higher CD4 counts.
- ◆ The study found no differences in the risk of disengagement by WHO stage at initiation, rural or urban setting, access to money for healthcare, marital status, or education.
- ◆ There were few reported **differences in preferences and experiences** between clients who were and were not continuously in care (data not shown)
- ◆ Half of participants said they would have liked **more information about HIV/more counselling**, with no difference by treatment outcome
- ◆ Two-thirds of participants would prefer to receive treatment outside the facility (in the community).
- ◆ Most participants had positive views of most aspects of their experiences at the facilities.
- ◆ Some participants expressed frustrations with clinic experiences:
 - ◆ Roughly two thirds of participants thought that clinic **queues were too long**
 - ◆ About 20% of participants felt that clinic staff do not treat patients with sufficient respect
- ◆ Regardless of outcome, 18% of participants noted that they find it difficult to admit to healthcare workers that they have missed ARV doses.

QUALITATIVE FINDINGS

FGD participants described barriers to retention at the individual, interpersonal, health facility, and community levels. Emergent barriers included:



- ◆ At the individual level, food scarcity and the cost of transport to the clinic.
- ◆ At the interpersonal level, stigma and non-disclosure, two inextricably linked phenomena.
- ◆ At facility level (wherein participants reported experiencing the most barriers), negative interactions with health facility staff, inefficiencies in clinic processes, and a fear of disclosure due to a lack of privacy.
- ◆ At the community level, employment conflicts, inability to take time off work for clinic visits or missing a day's income because of long clinic waiting times.

ILLUSTRATIVE QUOTES



Individual-level barriers

"I have trouble with **transportation money**. My date arrives and I don't have money for transport. I even go and borrow from a friend."

"The medication intake requires one to eat food, when you **do not have income to buy food**, it really becomes a problem. I am discouraged to collect my medication from the clinic, because I know that I will not take it since there is no food, So I might as well stay without the pills because of the lack of income"



Interpersonal-level barriers

"When I started taking treatment things changed at home. They had a discussion about me from day 1. I **was given my own plate and spoon**. I had my own things that I must use separately for everything I do in the house. So I am known as "that person on treatment" at home."

"Sometimes it happens that in a family **you are the only one like this**. What scares me is that I am the only one in the family with this problem. I can't open up and talk to a person that is HIV negative and tell them I am positive. It would have been easier if somebody else was dealing with the same problem in my family."

"It is hard just to tell even friends what is going on and that you are on medication. Sometimes you end **defaulting just to impress your family or the partner**. You want to be seen as innocent to your partner."



Health facility-level barriers

"But the problem started with the nurse who tested me.. When she finished testing me she was like "**you are busy with boys here**". She did not even know... So next time when they say go to the social worker, no thank you, because already you have judged me. You have categorised me, even if I was running around with boys, there was no need for you to say that."

"The problem is **the missing files at the clinics**. They will come and ask when you last attended the clinic when it is clearly stated on the appointment card. I am not sure how files go missing, but they do. You sit for 30 minutes whilst they are still looking for your file. People behind you will pass you and go in. You end up being attended late. There really needs to be another strategy when it comes to the filing system."

"What makes people to be anxious about going to the clinic is meeting people they know that work at the clinic. They worry about them spreading the information to other people they know. They feel like hiding so that they will not be seen by people that know them at the clinic. It would help if clinic staff **took the issue of confidentiality seriously**. That is the reason people do not like going to the clinic."



Community-level barriers

"My clinic date was on the 16th. **My boss does not care if it is your clinic date**. He wants you at work. So I wanted to leave work early, but I couldn't. When I got of the taxi, it was already 16h00. I figured it was too late to go to the clinic. On the next day I woke up early to collect my treatment. When I got there I was number 2 but could not get assistance because there were prioritising people that came after me with appointment cards. I got angry and asked them what was happening and they said that I will be seen last because I missed the date."

CONCLUSIONS

- ◆ About a quarter of HIV-positive adults initiating ART **do not remain continuously in care** during their first six months on treatment.
- ◆ Two thirds of the sample had viral load test results documented; of these, **71% were suppressed**.
- ◆ Few characteristics predict future interruptions or disengagement during the early treatment period; of those that do, lack of food security and long waiting times may be the most readily modifiable.
- ◆ **Stigma at every level** remains a common theme among clients struggling to remain continuously in care.
- ◆ Improvements at the facility level, including shorter waiting times and more welcoming staff, may also encourage retention in care.

Cite as: Maskew M, Mutanda N, Scott N, Morgan A, Benade M, Ntjikelane V, Sande L, Malala L, Manganye M, Rosen S. Drivers of disengagement from care during the first six months on antiretroviral therapy for HIV in South Africa. Retain6 Policy Brief, May 16, 2025.