

Session 3A 3.3 Reasons for re-engagement

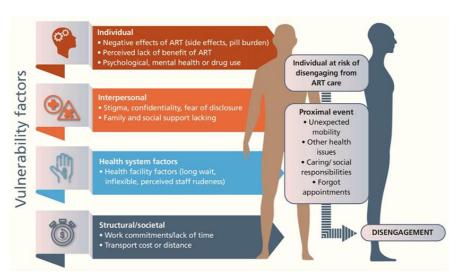


Reasons for disengagement

Unexpected Barriers:

- -Travel for funeral or work
- -Personal or family illness
- -Perceived clinic inflexibility
- -Similar barriers for treatment guardians

Missed ART Appointment



Burke et al 2024



Reasons for disengagement

Compared Barriers:

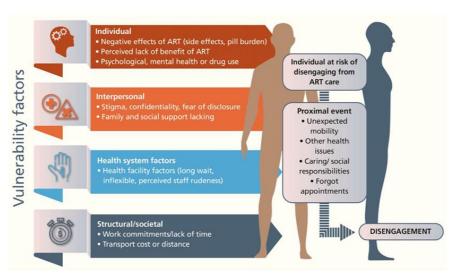
-Travel for funeral or work

-Personal or family illness

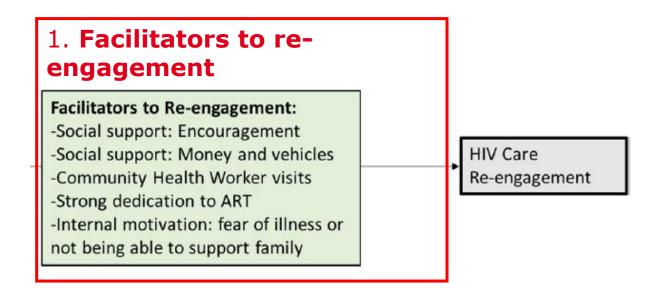
-Perceived clinic inflexibility

-Similar barriers for treatment guardians

Missed ART Appointment



Burke et al 2024



Reasons for disengagement

Unexpected Barriers:

- -Travel for funeral or work
- -Personal or family illness
- -Perceived clinic inflexibility
- -Similar barriers for treatment guardians

Missed ART Appointment

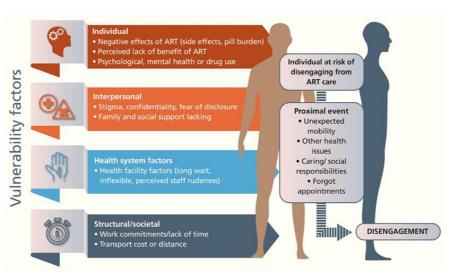
2. Barriers to timely re-engagement

reasons for prolonged disengagement

Barriers to Timely Re-engagement:

- Inflexible ART clinic schedule
- Limited clinic resources
- Lack of transportation money
- Other competing work or family priorities

Extended Time Away From Clinic



Burke et al 2024

1. Facilitators to reengagement

Facilitators to Re-engagement:

- -Social support: Encouragement
- -Social support: Money and vehicles
- -Community Health Worker visits
- Strong dedication to ART
- -Internal motivation: fear of illness or not being able to support family

HIV Care Re-engagement



Reasons for re-engagement

Personal motivation to re-engage

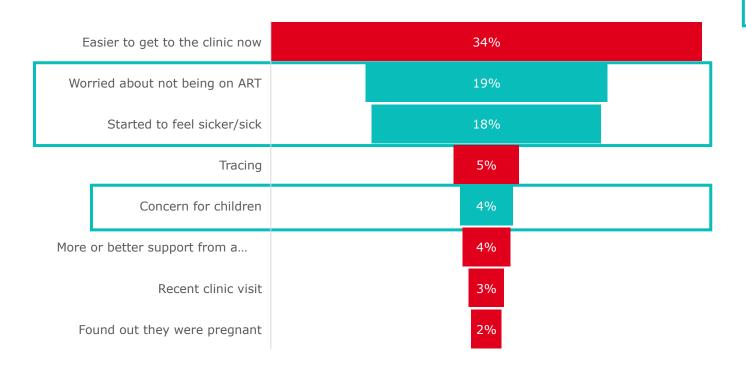
Barriers

-

Facilitators



Personal motivation to re-engage



Facilitators of Re-engagement

Fear of Illness and Concern for Family

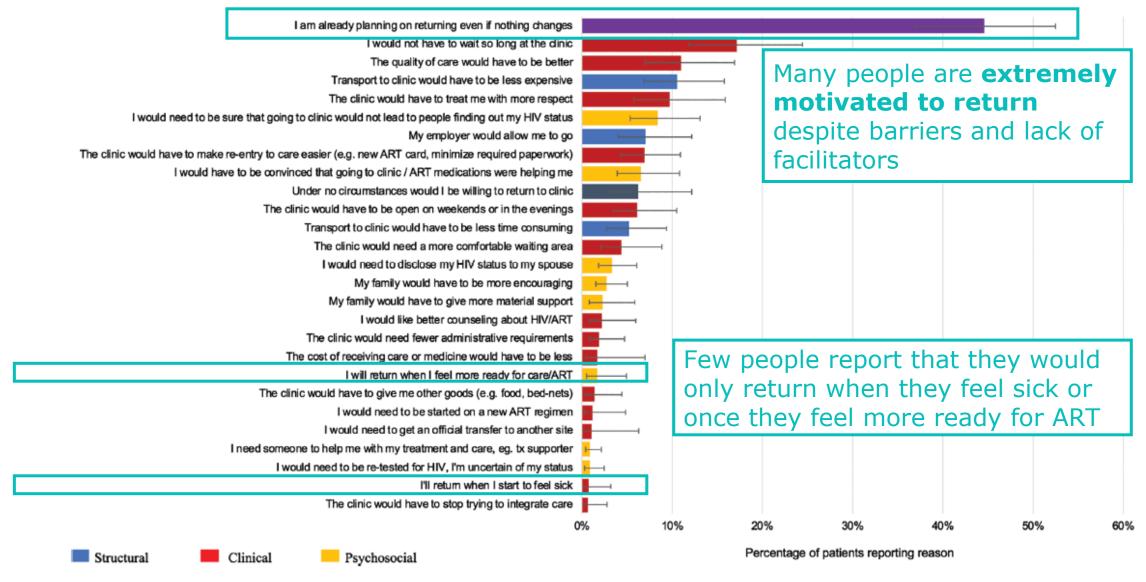
When asked why they returned to HIV care, almost all respondents reported a strong internal motivation because they feared that they could become ill or die if they did not take ART. Nearly three-quarters of respondents, equally distributed between men and women, expressed a desire to remain healthy in order to provide and care for their families as their primary motivation for re-engaging with HIV care.

"I have seen the importance of taking medicine because my body becomes different if I stay without taking medicine.... my body becomes weak...But if I take the medicine, I work with a lot of energy." (40-year-old, married man)

"I thought maybe I could die anytime. That means my children will become orphans." (47 year-old, unmarried woman)

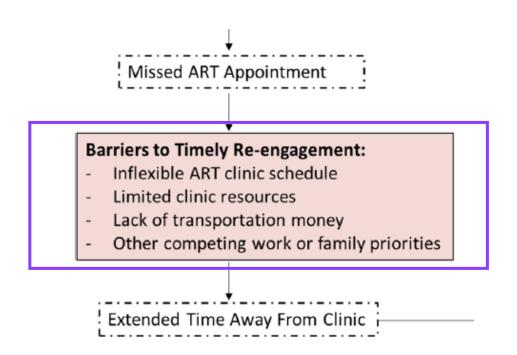
Chamberlain et al 2022







Barriers to re-engagement



prolonging dis-engagement

Limited Clinic Schedules and Resources

Respondents reported that limited clinic hours or inflexible appointment schedules constrained their ability to address their HIV care amidst unexpected life events. Nearly half of respondents, both men and women, referenced this as a broader challenge to engagement in HIV care. Below, we focus on situations where this posed a specific barrier to individuals' re-engagement in HIV care.

Just under a quarter of respondents, equally divided between men and women, reported that they returned to the health facility as soon as possible, but were turned away because they did not come on an ART clinic day or because an ART provider was not available for various reasons. In some



South Africa CLM data



Alarmingly, some people even report health workers denying them ARVs following a late or missed appointment. "We get punished for missing dates. I went to the clinic for five months without being helped." explained one person. Another woman explained how she asked for enough pills to last until her new appointment date but they refused. "I was devastated," she told us. "This month I missed my appointment because I was at work. I was sent away. Even now I have not received my pills," another person told us.

If you are late for an appointment at the facility or an ART refill collection at the facility or in the community, when you do return to the facility, which of the following happens:	Result	%
Staff are welcoming back	2909	49%
The staff shout at you for being late/missing the appointment date	688	12%
Staff counsel you on adherence	929	16%
Staff ask why you missed appt	1615	27%
Staff send you to back of queue	808	14%
The staff ask how they can help make it easier for you in future	402	7%
The staff offer you a longer supply of ART to make it easier	144	2%
The staff tell you about ART refill collection points closer to home or work that you can access which may make it easier	215	4%
The staff give you a shorter supply of ART than what you usually get (e.g. 1 month instead of 2 months)	52	1%
The staff refuse to give you ART on the day you return and require you to return more than once to get your ART	50	1%
Other	72	1%
PLHIV surveyed	5917	



Client perception of HCW negative response on return

Negative Interactions with Clinic Staff were Concerning, but not a Barrier to Re-engagment

"I was thinking that [the clinic staff] would feel like I have just stayed at home because I have not sent any message. You see, I was worried, but I [decided to] answer when they ask me. If they will not believe, then it is fine, but still I will explain why I failed to go and collect the ARVs on that day. I was worried that they would ask me questions or shout at me that I am being childish not to collect the ARVs." (21-year-old, married man)

don't patients who miss visits then return? A strong reluctance to return for care after an absence emerged from the qualitative data.

I was scared to come back to the clinic since a lot of time had already passed and I might come back and they chase me away. [Male, age 40] I was scared of coming back and them telling me that they will not accept me because I didn't come when they told me to. I was wondering whether they would accept me or not or whether they would scold me. [Female, age 35]

I was afraid to go back because I didn't have my card and I stopped meds for a long time. I was afraid the nurses would yell at me. [Female, age 35]

Perception of the HCW response at return impacts timeliness of re-engagement

Would go back anyway

Remained disengaged



Barriers prolong return until hospitalized with AHD

'They refused to give me a transfer because they cannot give me transfer twice in one year'. (Participant #3)

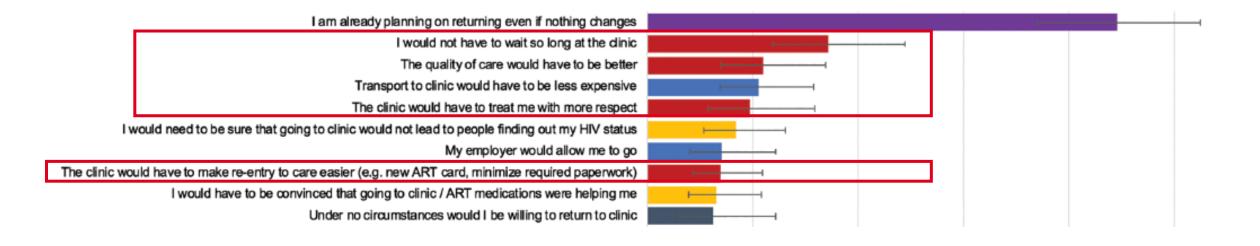
Another participant described how, if he was unable to get off work, he might be a day or two late for his appointment. When this happened, the reception he received at the clinic led to him disengaging in care, as described below:

"......but the shouting that came from the nurses during that time would make me feel as though I wasn't human." (Participant #7)

engagement following disengagement. One participant described going to a mobile clinic to pick up ART as she did not have the money to take a taxi to the fixed clinic. Mobile clinic staff refused to issue her with medication saying her file was at the fixed clinic. With the help of another patient, she "fooled" the system by pretending she did not know her HIV status. She was immediately offered HIV testing when she said she did not know her status. As a result, she was retested, retested positive and was issued with her ART. She describes her difficulties with the clinic staff at both locations below:

'The only issues we have are the clinics....... If you miss your appointment they shout at you at the clinic, even if you missed your appointment by a day, they still shout at you. They say "this isn't your appointment date, "and then you wonder how they work because sometimes you find that you still have a few pills left in the container and I explain that I took my pills, it's not that I did not take them because I would still have a few left. But they still shout at you irrespective. So those are the kind of nurses that we have to deal with'. (Participant #13)





Reasons to return to care

RED = health system barriers

BLUE barriers are cost related, these can also be reduced by longer ART supplies

Top YELLOW barrier could be supported by service delivery changes



Facilitators to re-engagement

Facilitators to Re-engagement:

- -Social support: Encouragement
- -Social support: Money and vehicles
- -Community Health Worker visits
- -Strong dedication to ART
- -Internal motivation: fear of illness or not being able to support family

Social Support and Encouragement to Return

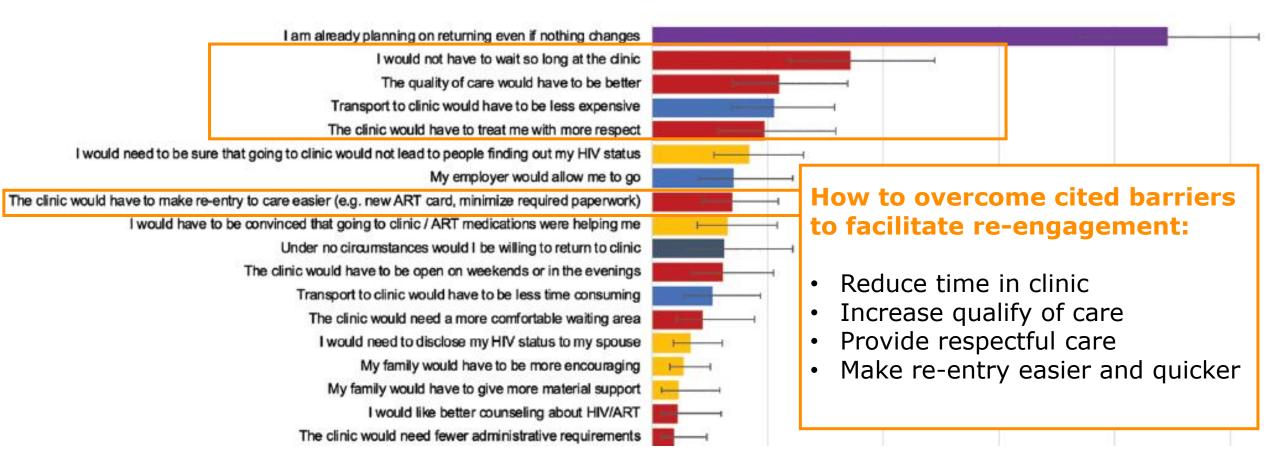
Emotional and financial support from respondents' social networks further facilitated their re-engagement. In the majority of cases, respondents disclosed their missed ART appointment to a friend or family member, and the ensuing conversations and support regarding ART services were central to their return to care. One-third of men and just under a quarter of women reported that a friend, family member, or boss encouraged them to return to the ART clinic as soon as possible.

Community Health Worker Outreach

Some respondents, mostly men, reported that a community health worker associated with the ART clinic encouraged them to return to care as soon as possible.

"So when the [community health worker] discovered that I am not coming, they came and picked me up to say 'You should start taking medicine again. We are surprised that you are not coming [to the clinic].' That is why I started taking medicine again." (40-year-old, married man)







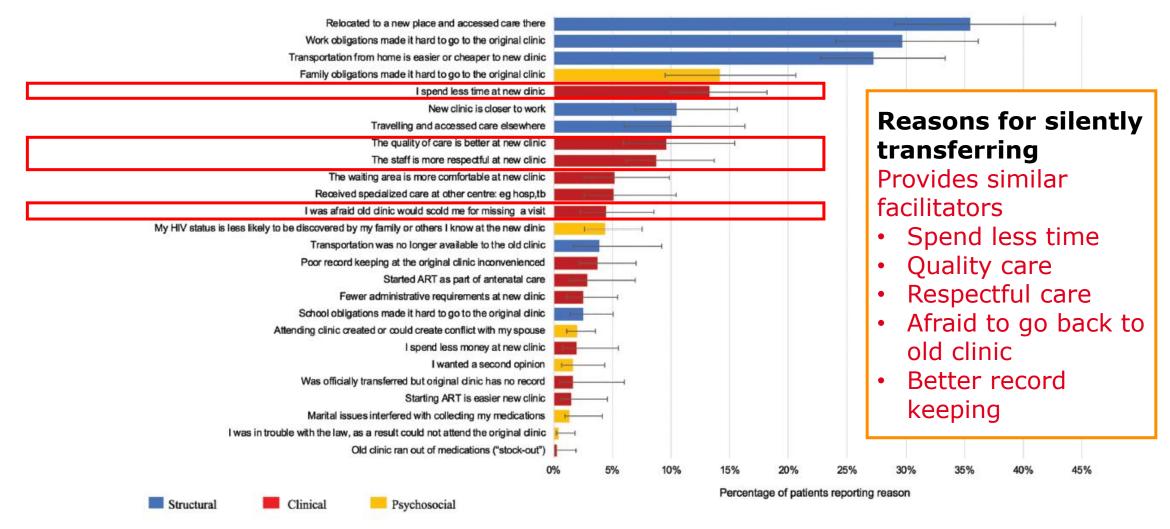
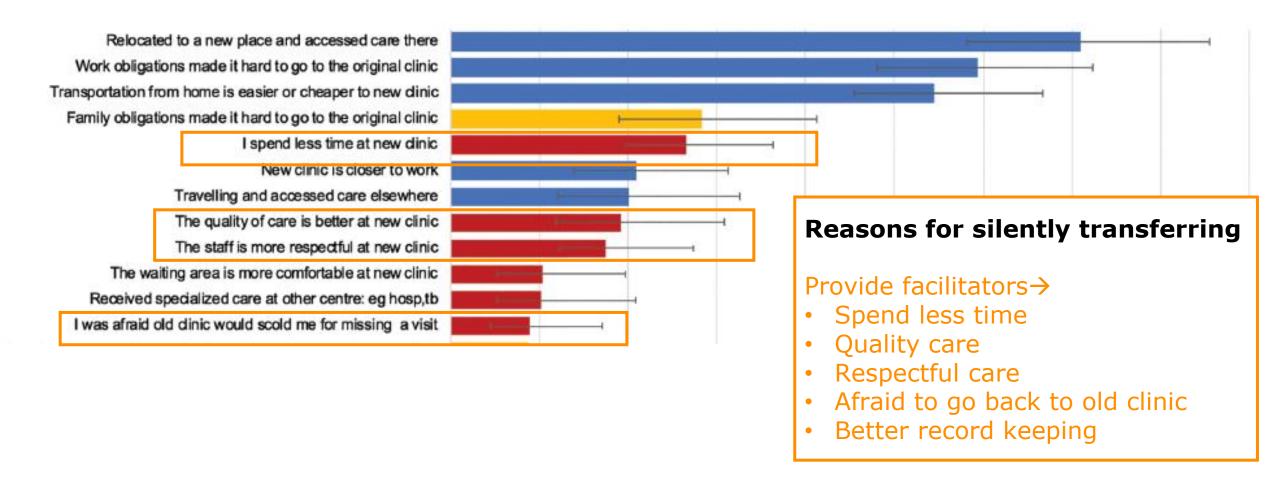


Figure 3. Reasons for silent transfer. n = 289. Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus.







Prolonged disengagement

Tracing
Hospitalization
Morbidity/mortality
Transmission



Easy, quick, durable returns

Personal motivation to re-engage

REMOVE

Barriers

ADD

Facilitators



Personal motivation to re-engage

Easy, quick, durable returns

REMOVE

Barriers

ADD

Facilitators

- →Prioritize respectful care for people returning and those observing others returning
- →Complete re-engagement on the day of return
- →Increase appointment schedule flexibilityboth when missing a visit & at return
- →Reduce waiting time at the clinic when returning
- →Don't intensify appointment schedule at return unless clinically necessary
- →Enable "silent" transfers