"Because my life is more important": Findings from a qualitative study on adherence to second and third-line antiretroviral therapy in Kenya, Malawi and Mozambique

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Background

- Little is known about treatment adherence behaviours amongst HIV patients on second and third-line antiretroviral therapy (ART) who may have unique experiences associated with reaching 'the end' of their treatment options.
- Understanding these behaviours is important for ensuring tailored support is available to patients after regimen switches in order to address previously experienced adherence barriers, and prolong the effectiveness of treatment.

Aim

- We explored influences on adherence to second- and third-line ART regimens among people living with HIV (PLHIV) enrolled in HIV programmes supported by Médecins sans Frontières in Kenya, Malawi and Mozambique.

Settings

- Homa Bay (Kenya) and Chiradzulu (Malawi): rural, most participants engaged in subsistence farming/fishing, petty trade.
- Maputo (Mozambique): urban, most participants engaged in formal employment.
- HIV treatment and care is provided through decentralised health centres in Malawi, and in district or referral hospitals in all sites.

Fig. 1: Study settings and HIV clinics in the 3 sites (from left to right: Homa Bay, Chiradzulu and Maputo)

Methods

- Repeated in-depth interviews (IDI) with 43 PLHIV on second- or third-line ART and 15 health workers across the 3 sites.
- Participants purposively sampled from second and third-line patients receiving their current regimen for at least 6 months, and ensuring diversity across age, sex, virological outcomes and antiretroviral regimen type (table 1).

Table 1: participants across sites

Group		Kenya	Malawi	Mozambique	Total
PLHIV	No virological failure[1] on 2nd line	5	4	4	**13**
	Virological failure[2]on 2nd line => no change, or switch to simplified/optimized 2nd line	6	4	5	**15**
	Virological failure[2] on 2nd line => switched to 3rd line	5	5	5	**15**
	Female	10	7	8	**25**
	Male	6	6	6	**18**
Health Workers	Clinical staff	2	4	2	**8**
	Counsellors and support staff	3	1	3	**7**
TOTAL		**21**	**18**	**19**	**58**

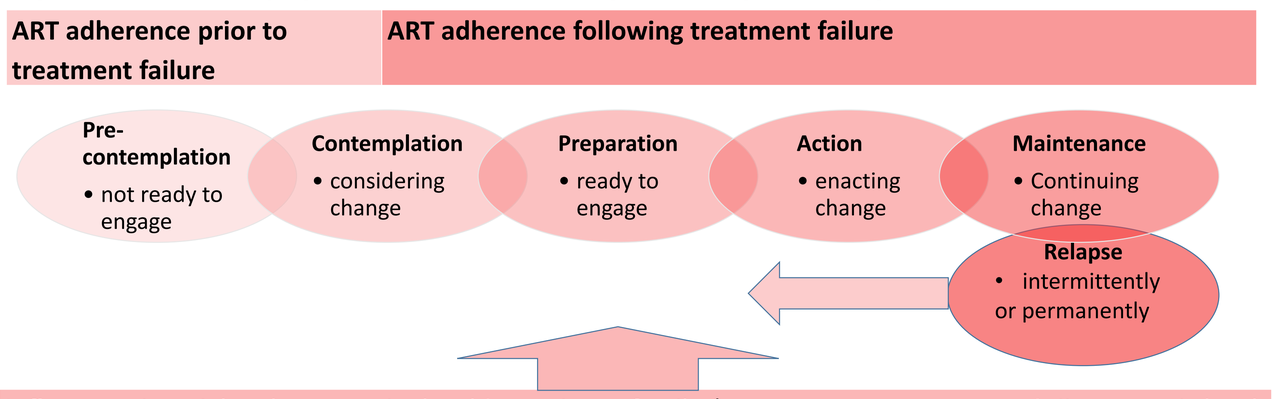
[1] <1000 cps/ml; ~12 months before IDI and at most recent VL test; [2] ≥ 1000 cps ~12 months before IDI

- Observations in clinic activities and group education sessions.
- Interviews audio-recorded, transcribed, translated into English.
- Data were coded inductively and analysed thematically.

Conceptual framework

We applied the stages of change model (transtheoretical model [1]) to consider the psychological processes underlying PLHIVs adherence to new ART regimens following treatment failure of first and/or second-line regimens, and the role of social, economic and health system influences in promoting or undermining this process (Figure 2).

Fig. 2: Process underlying ART adherence according to the stages of change model



Influences: i. social and community level (e.g. stigma, family /partner treatment support); ii. economic level (e.g. employment/mobility conflicting with care and treatment schedules, food availability); iii. health systems level (e.g. relations with health workers, ART messaging, side effects experienced)

Results

Contemplation and preparation: In all sites, patients' engagement with second and third-line ART was often shaped by experiencing life-threatening illnesses prior to switching regimens and being given "a final chance at life". These events, alongside viral load and CD4 results, could catalyze change in patients' attitudes to pill-taking and feelings of responsibility for managing their disease after regimen change.

"My CD4 decreased and viral load went up to 2000 copies. So that's when they called my husband, they said `it's better you talk to your wife because your wife is going to die '. And I was about to die. So then, in the hospital, my husband talked to me, I swore right there 'never again'. From that day, I was going to start taking the pills. And I started taking them normally, no problem." **[Woman, recently switched to 3rd line ART, Mozambique]**

Action: These feelings of responsibility often prompted lifestyle changes such as giving up drinking, changing jobs that could interfere with treatment and reducing sexual encounters. Other patients reported psychosocial transformations and overcoming community stigma, disclosing their HIV status to others or being driven by a desire to stay alive to bring up their children.

"I had to organize my duties and my responsibilities in accordance to my time of taking drugs. I was an ardent fisherman, but nowadays I am an ardent gardener" **[Man, on 2nd line ART with undetectable VL, Kenya]**

Transformations were often influenced by health workers' advice. Counselling approaches were found to support patients to change adherence behavior, especially in Kenya. However in many cases treatment messages detracted from patients linking treatment failure to their ART adherence:

"I felt a little embarrassed…I had already been told 'eish you must not drink, you had better to control your time schedule to take pill, you must not have sex without using a condom, you must not sleep after the normal sleeping time'. But…some of the things, I did not keep them. So it culminated with this result (treatment failure)." **[Man, recently switched to 3rd-line ART, Mozambique]**

Maintenance: some participants were able to maintain renewed commitment to second or third line ART.

"You are coming from far away, when they started giving you 2 months (ART refill)…was that a short length of time to come back to the clinic? *I am very flexible even if am given one day (ART refill) I will still be flexible because my life is more important."* **[Woman, on 2nd line ART with undetectable VL, Kenya]**

Relapse: However others risked relapsing given the persistence of multiple and interrelated social, economic and health systems challenges that had previously undermined their adherence. Increased side effects and greater pill burden associated with second and third-line regimens compounded patients' adherence challenges.

"They changed me to second line, when I took them I was having pains around the heart and I didn't adhere to them as well….they had to put me on third line. The only challenge at home now is food because if I take the medication without food I have complications. Food is always crucial for taking medication." **[Woman, recently switched to 3rd line ART, Malawi]**

Conclusion

- While well-established barriers to adherence remain for many patients after regimen change, others experienced a resurgence of hope as they overcame debilitating illness associated with prior treatment failure. Although this can initially encourage renewed efforts to adhere, the effects may wane over time.
- Correct health messages on treatment failure alongside regular, patient-centered counseling or peer-led mentoring interventions may help promote and sustain these life transformations and support adherence, thereby prolonging the life-span of second and third-line regimens.

References

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