

Temporary disengagement and re-engagement in human immunodeficiency virus care in a rural county serving pastoralist communities in Kenya: a retrospective cohort study

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Background: Pastoralist communities are known to be hard to reach. The magnitude of temporary disengagement from human immunodeficiency virus (HIV) care is understudied.

Methods: We conducted a retrospective cohort study of temporary disengagement (2 weeks late for a next appointment), virologic response, lost to follow-up (6 months late) and re-engagement in care among patients who started antiretroviral therapy between 2014 and 2016 in Baringo County, Kenya. Predictors of re-engagement after disengagement were estimated using logistic regression.

Results: Of 342 patients, 76.9% disengaged at least once (range 0–7). Of 218 patients with a viral load (VL), 78.0% had a suppressed VL. Those with a history of temporary disengagement from care were less likely to suppress their VL ($p=0.002$). Six patients had treatment failure (two consecutive VLs >1000 copies/mm³) and all had disengaged at least once. After disengagement from care, male patients (adjusted odds ratio [aOR] 0.3 [95% confidence interval {CI} 0.2 to 0.6]; $p<0.001$) and patients with World Health Organization stage III–IV (aOR 0.3 [95% CI 0.1 to 0.5]; $p<0.001$) were less likely to re-engage in care.

Conclusions: Temporary disengagement was frequent in this pastoralist setting. This indicator is often overlooked, as most studies only report binary outcomes, such as retention in care. Innovative strategies are required to achieve HIV control in rural settings like this pastoralist setting.

Keywords: antiretroviral therapy, information management, medication adherence, patient compliance, rural population, treatment outcome

Introduction

The large-scale rollout of antiretroviral therapy (ART) has greatly contributed to saving the lives of millions of people living with human immunodeficiency virus (HIV).¹ However, most HIV programmes and studies assess success, in terms of retention on ART or viral suppression, at a given moment during follow-up and ignore disengagement from care when this is followed by re-engagement.^{2,3}

In low-resource settings, people living with HIV on ART face a myriad of economic, social, geographical and health system challenges, a phenomenon that compromises their consistency of engagement in care.⁴ In addition, patients on ART may be less motivated once their health status has recovered or when

they experience ‘treatment fatigue’.⁵ After stopping ART, some patients overcome challenges and re-engage in care. However, some challenges are more difficult to overcome than others.

Limited literature exists on the magnitude of disengagement from care when followed by re-engagement. In one East African study, patients lost to follow-up (LTFU) were interviewed. The study found that patients are more likely to overcome structural barriers, such as poverty or health system-related barriers, than personal barriers, such as treatment fatigue or the belief that one does not need care anymore.⁶ A South African study showed the importance of taking into account that a patient’s trajectory may be irregular, as perceived needs and factors that influence decision making may change over time.⁷ Only a few studies have quantified the proportion of patients who

temporarily disengaged from care. A South African study found that one in four patients disengaged at least once in a 2-y period. Of those who disengaged, one-third re-engaged during the 2-y study period.⁸ In a large ART cohort in Uganda followed for a median of 3 y, 11.2% of patients disengaged from care for at least 12 months. Of those who disengaged, >70% returned to care.⁹ However, patients may disengage from care more than once during follow-up, especially when personal or structural barriers are not 'resolved'. Although the above studies evaluated the frequency of temporary disengagement from care within a given cohort, none quantified the frequency of temporary disengagement from care at the patient level.

In terms of the number of people living with HIV, Kenya is reported to have the fourth largest HIV epidemic globally. With a prevalence of 4.5%, Kenya counts 1.5 million people living with HIV. In 2018, 75% of all people living with HIV were on ART and 63% had a suppressed viral load (VL).¹ However, some communities may be harder to reach than others. In particular, rural settings with less well-developed health infrastructure and mobile populations, such as pastoralist communities, are known to be hard to reach.¹⁰ Adherence to long-term treatment may be suboptimal.¹¹ No previous study has assessed the frequency of temporary disengagement from care in the setting of pastoralist communities.

In a rural county in Kenya with pastoralist communities, we studied temporary disengagement from HIV care at the Baringo County Referral Hospital. We quantified how frequently patients disengaged from care and estimated the factors associated with re-engagement in care. We also studied the relation between having a history of temporary disengagement and virologic response.

Methods

Study design

This was a retrospective cohort study.

Study setting

Baringo County is a rural county located in the North Rift region of Kenya. It has a total population of about 679 000, with an overall HIV prevalence of 1.6% (2.3% among women and 1.4% among men).¹ The Ministry of Health introduced ART into the county in 2003. There are 187 health facilities, of which 36 provide ART. Baringo County has an estimated 5586 people living with HIV. In 2015 a total of 2668 patients were on ART, translating to a county ART coverage of 58%.¹² In 2016 the Ministry of Health recommended ART initiation regardless of the CD4 count.

The Baringo County Referral Hospital is the referral hospital for specialized clinical care in the county. HIV care is provided both through a dedicated outpatient comprehensive care clinic, which follows up 2000 HIV-infected patients, and the internal medicine inpatient wards. The ART drug supply is normally through the Kenya Medicines Supply Agency, responsible for the procurement and supply of medicines to all public hospitals in Kenya. Procurement and supply are informed by monthly reports, which are submitted through the Demographic Health Information System. The first-line regimen used most often within the study period was a fixed-dose combination of

tenofovir disoproxil fumarate (TDF), lamivudine (3TC) and a 600-mg dose of efavirenz (EFV).

Two clinical officers who have undergone additional training in HIV care and treatment run the clinic. When a patient is enrolled into care, he/she first undergoes counselling, after which he/she is referred to the clinical officer. Newly diagnosed people living with HIV or patients re-engaging in care start ART in the wards of the clinic. Before starting ART, the clinical officer requests various investigations (including a CD4 count). One month after starting ART, the first follow-up visit is scheduled. Patients receive buffer pills for 2 d of treatment. The next two appointments are scheduled 3 months apart. Thereafter visits are planned every 6 months. One of the adherence counsellors traces patients missing a clinic appointment 2 weeks after the scheduled visit date. Patients who show missed appointments or who temporarily disengage from care are referred for additional adherence counselling.

Data collection and analysis

Data were collected retrospectively from both the patient files and electronic records. Patients were included if they started ART between 1 January 2014 and 31 June 2016 and were followed until 30 June 2017. The collected data included a unique identifier, gender, age, distance between home and the clinic, the date of ART initiation, the last visit date, the last next appointment date, baseline (pretreatment) World Health Organization (WHO) clinical stage (I–IV), CD4 results and dates, VL results and dates, the frequency of temporary disengagement from care and the treatment outcome.

Each time a patient was 2 weeks late for a next appointment, the patient was considered as having disengaged temporarily from care. For each patient, the frequency of disengagement was counted. Those who returned to care after temporary disengagement were considered to be re-engaged in care. Patients could disengage and re-engage multiple times during the study period. Those who did not re-engage in care and who were >6 months late for their next appointment at the end of the study period were considered LTFU, unless tracing showed they had died or were in care at another health facility. Those who were in time for their last next appointment date at the end of the study period were considered to be active in care. Virologic failure was declared in patients with two consecutive VLs >1000 copies/mm³.

We calculated medians and interquartile ranges to summarize continuous variables and proportions for categorical variables. Kaplan–Meier statistics were used to estimate attrition (either death or LTFU) at 6, 12 and 24 months on ART. Patients active on ART at the end of their study and transferred out were censored. Patients who died or were LTFU were considered having had the event. Follow-up time was calculated as the time between ART initiation and the last next appointment date. Among patients disengaged from care, we assessed factors associated with 're-engagement in care' against becoming LTFU using a multivariable logistic regression model. Patients with an unclear treatment outcome (>2 weeks late for the next appointment but not declared LTFU at the end of the study period) and those who died or transferred out were excluded from

this regression. Using backwards elimination, factors were only retained in the multivariable model when significantly associated with staying LTFU. Associations were considered significant at $p < 0.05$.

Ethics

Study procedures followed were in accordance with the ethical standards of the Helsinki Declaration. The study was approved by the Institute of Tropical Medicine Institutional Review Board (1171/17), the Ethics Committee of the Antwerp University Hospital (17/21/259) and the Joint Institutional Research and Ethics Committee of Moi University and Moi Teaching and Referral Hospital (IEC 1971). The requirement to collect informed consent was waived by the respective ethics committees. Confidentiality was ensured. Clinicians responsible for the daily care of the study participants encoded the study database. The study database contained coded data, including a numeric identifier.

Results

Data were collected from 344 patients. Two were excluded, because the treatment outcome was unknown. Of the remaining 342, most (202 [74.3%]) were female (Table 1). The median age of the patients was 41 y (interquartile range [IQR] 34–48). Of the 342 patients, 135 (39.5%) started ART in 2016, when ART was started irrespective of the CD4 count. The median distance between the patient's home and the clinic was 12.0 km (IQR 2.5–27.5). The median baseline CD4 count was 207 cells/mm³ (IQR 232–314).

At the end of the study period, 166 (48.5%) patients were active in care, 34 (9.9%) had an unclear outcome (>2 weeks late but <6 months), 113 (33.0%) were LTFU (>6 months late), 6 (1.8%) were transferred to another clinic and 23 (6.7%) had died (Figure 1). The 6-, 12- and 24-month attrition rates were 20.0% (95% confidence interval [CI] 16.1 to 24.7), 30.2% (95% CI 25.6 to 35.5) and 38.0% (95% CI 32.7 to 44.0), respectively.

The vast majority of patients (76.9% [263/342]) disengaged at least once during the study period (Table 1). Among all 342 patients, the frequency of treatment disengagements ranged from 0 to 7 (median 1 [IQR 1–2]). Of 166 patients active in care at the end of the study period, 105 (63.3%) disengaged at least once and then re-engaged.

Overall, 63.7% (218/432) had a VL during the study period. VL coverage was similar in those with or without a history of disengagement from care (62.0% vs 69.6%; $p = 0.2$). In patients with a VL, 78.0% (170/218) had a suppressed VL and 18.8% (41/218) had a VL >1000 copies/mm³. Patients who disengaged at least once from care were more likely to have a VL >1000 copies/mm³ (22.7% vs 7.3%; $p = 0.01$). Of 41 patients with a VL >1000 copies/mm³, 31.7% (13/41) had a follow-up VL result. All six patients with a follow-up VL >1000 copies/mm³, thus with virologic failure, had disengaged at least once (range 1–5) (Figure 1).

Among 263 patients with a history of disengagement from care, 34 were still late for their next appointment (thus neither re-engaged nor LTFU), 9 had died and 2 were transferred out at the end of the study period. Among the remaining 218, 105 (48.2%) re-engaged in care and the other 113 (51.8%) were declared LTFU. Male patients (adjusted odds ratio [aOR] 2.9 [95% CI 1.6 to 5.3] and patients with a WHO stage of III or IV (aOR 3.7 [95% CI 1.7 to 8.1]) were more likely to not re-engage

Table 1. Baseline characteristics, by history of disengagement from care, in 342 patients on ART between January 2014 and June 2017, Baringo County, Kenya

Characteristics	Total	With a history of disengagement from care	Without disengagement
Total, N	342	263	79
Gender, n (%)			
Female	202 (59.1)	159 (60.5)	43 (54.4)
Male	140 (40.9)	104 (39.5)	36 (45.6)
Age (years), median (IQR)	41 (34–48)	41 (34–48)	39 (35–47)
Distance between home and the clinic (km), median (IQR)	12 (2.5–27.5)	12 (3–27.5)	13.5 (1–26.5)
Baseline CD4 count (cells/mm ³), median (IQR)	207 (82–314)	214 (87–323)	182 (45–307)
Baseline WHO staging, n (%)			
I and II	275 (80.4)	209 (79.5)	66 (83.5)
III and IV	66 (19.3)	53 (20.2)	13 (16.5)
Unknown	1 (0.3)	1 (0.4)	0 (0.0)
Year ART start, n (%)			
2014	88 (25.7)	69 (26.2)	19 (24.0)
2015	119 (34.8)	98 (37.3)	21 (26.6)
2016	135 (39.5)	96 (36.5)	39 (49.4)

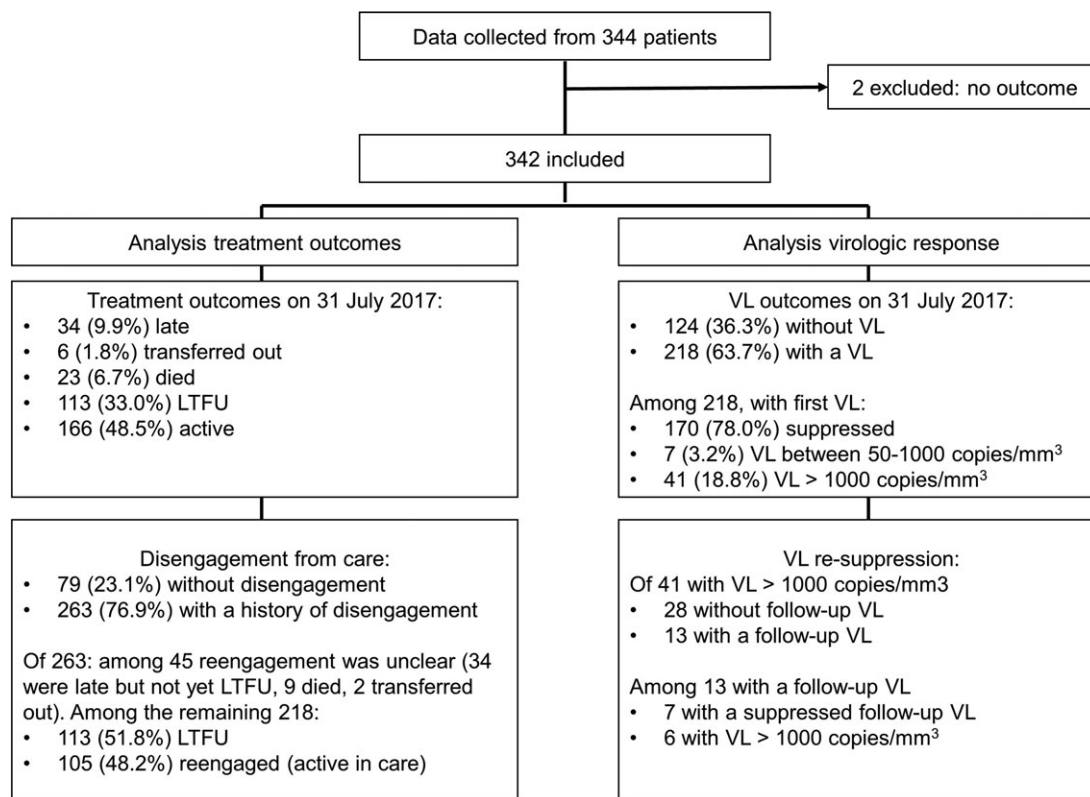


Figure 1. Treatment and virologic outcomes among patients who started ART at the Baringo County Referral Hospital between 1 January 2014 and 31 June 2016.

in care. The distance between the patient's home and the clinic was not associated with re-engagement (Table 2).

Discussion

Temporary disengagement was very frequent in this population. The vast majority (76.9%) of patients disengaged at least once and some patients disengaged up to seven times. Lack of viral suppression was significantly associated with disengagement from care. After disengagement, male patients and patients with an advanced WHO stage were noted to have higher odds of not re-engaging in care. Indeed, male patients are harder to reach, more difficult to retain and less likely to re-engage in care.^{8,13,14} In our study, patients with a low CD4 count were less likely to re-engage. We speculate that a substantial proportion of patients with advanced disease and not on ART died in the community. Patients with advanced disease may have difficulties reaching the clinic, especially in rural areas.⁴ The opposite is true as well. Non-adherence and disengagement from care are associated with morbidity and mortality: a recent large-scale UK study showed that patients who spent a lower cumulative proportion of follow-up time in care were more at risk to die.¹⁵

Our findings suggest that a radical review of the care model is needed to be able to achieve the 90-90-90 Joint United Nations Programme on HIV/AIDS (UNAIDS) targets in this pastoralist community in Baringo County. When we extrapolate our findings, an estimated 45% of all people living with HIV have a

suppressed VL (of all people living with HIV, 58% are on ART¹² and of those, 78% have a suppressed VL). Thus it may be important to consult patients and adapt the care model to the specific needs, expectations and customs of people living with HIV in pastoralist communities. The Sustainable East Africa Research in Community Health (SEARCH) trial, conducted in rural Uganda and Kenya, showed that when testing and treatment modalities are adapted to overcome structural and psychosocial barriers, the uptake and utilization of HIV testing and treatment services can increase and the UNAIDS targets can be met.¹⁶ Additional studies are needed to assess if lessons learned from the SEARCH trial can be applied to pastoralist communities and how delivery should be adapted to fit local needs and expectations. One strategy that worked in other rural communities, the Community ART Groups, relied on the active involvement of peer groups in drug pickup at the health facility and drug distribution in the community. Retention was higher in this community-based delivery model than in conventional facility-based care, as peers supported each other to overcome daily barriers to care.¹⁷ However, a peer-led care model adapted to the needs of people living with HIV in pastoralist communities can only be successful if community stakeholders and patients are involved in the design, planning and implementation.¹⁸

Missed scheduled visits is an important measure of ART adherence, but is often overlooked.¹⁸ Most studies only report binary outcomes, for example 'retention in care at the end of the study period' or 'retention at 12 or 24 months ART'.¹⁹ Consistent with UNAIDS guidelines,²⁰ other studies propose HIV

Table 2. Factors associated with not re-engaging in care (thus declared LTFU) in 218 patients who disengaged from care

Factors	Re-engagement in care	LTFU	OR (95% CI)	aOR (95% CI)
Total, n (%) ^a	105 (48.2)	113 (51.8)		
Gender, n (%)				
Female	80 (58.4)	57 (41.6)	1	1
Male	25 (30.9)	56 (69.1)	3.1 ^{***} (1.8 to 5.6)	2.9 ^{***} (1.6 to 5.3)
Age (years), median (IQR)	42 (35–47)	40 (33–49)	0.9 ^e (0.7 to 1.2)	NS
Distance between home and the clinic (km), ^b median (IQR)	13 (3–25)	12 (1–31)	1.0 ^e (0.9 to 1.1)	NS
Baseline CD4 count in cells/mm ³ , ^c median (IQR)	251 (115–344)	203 (94–289)	0.9 ^f (0.7 to 1.0)	NS
Baseline WHO staging, ^d n (%)				
I and II	95 (54.6)	79 (45.4)	1	1
III and IV	10 (23.3)	33 (76.7)	4.0 ^{**} (1.8 to 8.6)	3.7 ^{**} (1.7 to 8.1)
Year ART start, n (%)				
2014	35 (59.3)	24 (40.7)	1	NS
2015	39 (48.2)	42 (51.8)	1.6 (0.8 to 3.1)	NS
2016	39 (50.0)	39 (50)	1.5 (0.7 to 2.9)	NS

^aPatients with an unclear outcome (between 2 weeks and 6 months late for their next appointment) and those who died or transferred out were excluded from this analysis. LTFU was defined as being >6 months late for the next appointment.

^bMissing data for 15 patients.

^cMissing data for 6 patients.

^dMissing data for 1 patient.

^eFor every increase of 10 units (either years or km).

^fFor every increase of 100 cells/mm³.

*p<0.05, **p<0.01, ***p<0.001.

NS: not significant.

care cascades to monitor uptake and response.³ None of these approaches would identify a history of temporary disengagement (followed by re-engagement) as a cause of inadequate treatment response.

Our study has some important strengths. The findings represent the reality of the ART programme serving pastoralist communities in Kenya. Although values for some variables were missing for a few patients, completeness was high for most variables. On the other hand, uptake of routine VL monitoring was limited, as in many other African settings.^{21,22} Moreover, our findings may not be generalizable to other programmes serving pastoralist communities.

Conclusions

The vast majority (76.9%) of all patients on ART in this pastoralist setting disengaged from care at least once. Disengagement was associated with virologic failure. Only 45% of all people living with HIV have a suppressed VL in Baringo County (58% ART coverage, 78% viral suppression among people living with HIV on ART). Innovative strategies are required to improve the UNAIDS 90-90-90 targets in this pastoralist setting. The frequency of temporary disengagement is an important indicator of HIV programme performance, but is often overlooked, as most studies only report binary outcomes, such as retention in care.

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