

Full Length Research Paper

# Patient retention on anti-retroviral therapy (ART): Experience of treatment centres (TCs) in Yaounde, Cameroon

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Despite the achievements of Anti-retroviral Treatment (ART) scale-up programmes for HIV/AIDS, retention remains a challenge. Achievements of the "90-90" HIV targets for the sustainable development goals hinges on adherence. Despite the importance of indefinite retention of patients in care, 33% of HIV patients in Cameroon are still lost-to-follow-up, thereby compromising scale-up initiatives. This study analyses data of patients on ART in Treatment Centres (TCs) and the associated loss-to-follow-up factors and proposes measures to address them. This research was a retrospective analysis of data from selected HIV/AIDS TCs. After obtaining consent, questionnaires were filled by participating TCs. Collected data were analysed using SPSS and figures were expressed as bar charts, and histograms. Five out of seven TCs participated, giving a participation rate of 71.4%. Of the 12,165 patients, 11,852 (97.4%) were adults (28.0% males and 69.4% females) while 313 (2.6%) were children. A total of 232 (1.9%) were lost-to-follow-up and 38 died within six to twelve months. Possible causes of loss-to-follow-up included poor treatment and adherence counselling, ignorance, stigmatisation, financial hardship and traditional and religious beliefs. All TCs reported transfer into and out of their centre, caused by distance, nature of job, and overcrowding. Concerns of attrition rates throughout the continuum of care from diagnosis to long-term retention are corroborated by other studies. Such attrition compromises gains from ART scale-up, leading to poorer health outcomes and wastage of limited resources. Therefore, instituting sustained counselling and education services, addressing social determinants and building on social support factors provide measures to improve retention

Key words: Retention, anti-retroviral therapy, treatment, loss-to-follow-up.

# INTRODUCTION

Although there has been significant reduction in HIVrelated morbidity, mortality, transmission, stigma and improved quality of life of people living with HIV/AIDS (PLWHA), prevalence and incidence remain unacceptably high (Gosset et al., 2019; Kaiser Family Foundation, 2019; Luchuo et al., 2017; Wung et al., 2016; Mbuagbaw et al., 2013; UNAIDS, 2013; Mosoko et al., 2011; Lessells et al., 2011). In response, many countries have been engaged in programmes to scale-up and maintain patients on Antiretroviral Treatment (ART) (Yehia et al., 2015), with 68% of adults patients and 53% of children patients receiving ART in 2019 globally (WHO, 2020;

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Author(s) agree that this article remain permanently open access under the terms of the <u>Creative Commons Attribution</u> <u>License 4.0 International License</u> Kaiser Family Foundation, 2019; UNAIDS, 2018b). As reported by Clouse et al. (2013) and Elvin et al. (2010), retention in HIV care contributes to viral load reduction or replication, prevention of transmission to others, prevents medication interruptions, maintain immunologic benefits, prevent HIV resistance, and monitor the effects of therapy. Other studies by Mosoko et al. (2011) and Matthew and Sydney (2010) have revealed that ART has led to suppression of viral replication, thereby dramatically extending survival. Despite the benefits of retention on ART, only 50-75% of HIV-infected patients in the United States (U.S.) met retention standards (Yehia et al., 2015), escape from medication side effects being one of the reasons (WHO, 2013). Studies have revealed that about 50% of HIV-infected individuals are not engaged in regular HIV treatment, while one-third fail to access care in three years consecutively (WHO, 2020), making sustained engagement impossible hence. (Cheever, 2007).

More than 7.5 million out of about 23.5 million PLWHA in Africa were placed on ART by the end of 2012, compared to only 50,000 a decade ago, with a 50% decrease in HIV-related mortality from when the drug became available (Kathryn et al., 2015). Despite reported medication adherence in Africa resulting from scale-up of ART, (Charurat et al., 2010), research in 37 sub-Saharan African countries reveal that only 65% of those initiated on treatment were retained, thereby introducing gaps in the diagnosis-to-treatment cascade (Kathryn et al, 2015). Dropout rates were more common among younger age, and male sex and those who use intravenous drugs (Fleishman et al., 2012).

Although massive scale-up of ART has occurred in resource-limited settings, understanding the extent of care and reducing loss to follow up LTFU remain huge challenges (Mazvita et al., 2015; Elvin et al., 2010; Cheever, 2007), resulting in 2-59% non-death LTFU in sub-Saharan Africa (Tsague et al., 2008). A systematic review and meta-analysis of low and middle-income countries by Matthew and Sydney (2015), reveals an overall patient retention drop of about 83, 74 and 68% in 12, 24 and 36 months respectively with duration in care. Bezabhe et al. (2014), reported similar findings in Ethiopia while Kathryn et al. (2015), also found that service coverage and access, quality and coordination of care, patient tracking, support to PLWHA and medical management influenced patient retention in Kenya, Malawi, South Africa, Uganda, Tanzania and Zimbabwe. Similar results were reported across sub-Saharan Africa, with patient retention in treatment receiving little attention after launch of the first large-scale ART programmes (UNAIDS, 2013; Rosen et al., 2007). Poor retention is therefore a huge threat to the sustainability of HIV treatment programmes in Africa (Matthew and Sydney, 2015).

With an HIV prevalence of 4.5% (the highest in West and Central African sub regions), (Wung et al., 2016), Cameroon government initiated the scale-up of ART through cost reduction in 2002, leading to an increase in the number of patients on ART (Bekolo et al., 2013; Mosoko et al., 2011). However, scale-up initiatives in Cameroon have been focused mostly on initiation into treatment and is also compromised by socioeconomic disparities (Thomas et al., 2007), patient discrimination, stigmatization, education, poor access to quality drugs, and poor staffing (Wung et al., 2016). This contributed to dropout from ART, especially in the months immediately after initiation when mortality is known to be high (Matthew and Sydney, 2010). Despite the importance of indefinitely retaining HIV patients in care, the average national proportion of loss to follow up (LTFU) of HIV/AIDS patients on ART in Cameroon is 33% (Bekolo et al., 2013). Due to poor retention, an estimated threequarters of adults living with HIV in sub-Saharan Africa (25% in Cameroon), have not achieved viral suppression (WHO, 2020; UNAIDS, 2013; Mosoko et al., 2011). Although gains were made from the scale-up on ART. LTFU remains a major challenge in resource-limited settings like Cameroon (Bekolo et al., 2013). Many concepts surround HIV care and within the context of this study,

(i) loss to follow-up (LTFU) is defined as "any patients who had been followed up at the sentinel site, but lost contact with the health facility for 180 days or more since their last recorded expected date of return" either by error in a computer tracking system or by being incommunicado, (Mazvita et al., 2015; Tsague et al., 2008).

(ii) Retention is the ability of a provider or care system to maintain a continuous relationship with a patient, measured by the number of medical appointments kept or missed from diagnosis to entry into care (UNAIDS, 2018a; Cheever, 2007).

(iii) Adherence to a medication regimen is defined as "the act of conforming to the recommendations made by the provider with respect to timing, dosage, and frequency of medication taking" (Bezabhe et al., 2014).

Poor adherence to ART creates drug resistance, compromises viral load suppression, (Brown et al., 2019; Tenthani et al., 2014; Benjamin, 2014) and increases virus transmissibility, and associated costs (Mbuagbaw et al., 2013; Matthew and Sydney, 2010), thereby exposing the patients to full blown AIDS (Kathryn et al., 2015; Clouse et al., 2013; Mbuagbaw et al., 2013; Matthew and Sydney, 2010). While some dropout patients die, some are exposed to higher risk of morbidity (Matthew and Sydney, 2010; Rosen et al., 2007), leading to negation of the gains sought by programme funders. Overall, successful achievement of the 90-90-90 target as revealed by Gosset et al (2019) and UNAIDS (2014), particularly the second target (90% of all HIV diagnosed infection cases will receive sustained antiretroviral therapy), hinges on patient retention (UNAIDS, 2014; Kaiser Family Foundation, 2019; UNAIDS, 2018a; WHO,

2013). A large and growing body of research points to poor retention as one of the crucial determinants of the overall impact of treatment (Matthew and Sydney, 2015; Bekolo et al., 2013). This study is an analysis of Treatment Centre data on patient retention on ART, associated factors and possible suggestions to improve retention.

#### METHODOLOGY

### **Study location**

The study was conducted in five Treatment Centres (TCs) in Yaounde, Cameroon. Of the five TCs, one (CNPS Hospital, Essos) is a parastatal, three (Djoungolo District Hospital, CMA Elig-Essono, and CMA Mvog-Ada) are government institutions and one (Hope Services Clinic and Maternity) is of the private sector. These TCs receive both adults and children patients, perform general in and outpatient services, with HIV care as one of the services. The oldest TC had been offering treatment for ten years (CNPS Hospital, Essos) while Djoungolo District Hospital for 5 years, CMA Elig-Essono for 4 years, and both CMA Mvog-Ada and Hope Services Clinic and Maternity for 2 years, giving an average duration of 4.6 years as TC. With respect to frequency of visits, individual patients do refill monthly depending on when the patients engaged on treatment.

#### Study design and sampling

This research was a retrospective analysis of data from five Treatment Centres in Yaounde, Cameroon. Sampling was convenient and purposive, intended to capture only TCs which consented. Letters of invitation to participate were given to seven TCs, one from each of the seven Sub-Divisions in Yaounde. All the seven TCs invited the research team and based on timing and convenience, five consented through letters from their directorates. After ethical clearance, visits were made to the Treatment Centres (TCs) which consented and appointments taken for data collection.

#### **Data collection**

Open-ended questionnaires (Data Extraction Form), designed for this study were pilot-tested in two TCs, not participating in the main study. Questions were then reviewed and adjusted to ease understanding. Prior visits by the research team permitted the TC administrators to schedule an appointment date for data collection. The process involved extraction of data from records of patients receiving ART at participating TCs. Data managers of TCs extracted information from records and filled into open-ended questionnaire, providing explanation where needed. For each TC, the questionnaire captured clinic name, location, duration in HIV care, number of patients, age range of patients, frequency of treatment, number of dropout cases, and deaths after dropout. It also captured transfer of patients into and out of clinics, reasons for transfers, reasons for drop out as suspected by TCs and proposed strategies to retain patients in care. Filled questionnaires were collected, cross-checked and errors corrected.

#### Data analysis

Prior to data entry, data were double-checked to reduce error margins. Collected data was analysed using SPSS and expressed

as in tables and bar charts.

#### **Ethical consideration**

Participation by TCs was voluntary and written consent was sought and obtained from TCs, with the freedom to opt out if uncomfortable to continue. Administrative authorization was obtained from the Regional Delegation of Public Health. The researchers did not have direct access to the records of patients nor any patients. Data were extracted by workers of the TCs from coded and certified records without patient names. Such records are often inspected and certified by teams from the Ministry of Public Health during evaluation.

## RESULTS

Of the seven TCs contacted, five (one private clinic, one parastatal and three were government hospitals), participated in the study, giving a participation rate of 71.4%. A total of eleven respondents, two in each of four TCs and three in one TC filled the questionnaire. Of the respondents, 6 (54.5%) were females and 5 (45.5%) were males. Ten (90.9%) of the respondents had degree level and above except one (0.9%) who had a Higher National Diploma. Years of experience in HIV care ranged from 8 to 19, with 9 (81.8%) having experience of 10 years and above. A total of 12,165 patients (Table 1) were found to have been on treatment in these five TCs within the last 6 months (October 2019 - March 2020), with age range of 2- 86 years and median age of 44 years.

All TCs had patients in the lowest and highest age ranges except CMA Elig-Essono where the youngest patient was 24 years old. The highest number of patients (6,105) was at CNPS Hospital, Essos and the lowest (400) at CMA Mvog-Ada. Adults and children were found in all TCs, with 97.4% adults and 2.6% children (Table 2). CNPS Hospital had the highest number of both adults (49.3% of total adults) and children (85.3% of total children) patients, while Hope Services Clinic and Maternity had the lowest.

## Patient dropouts or LTFU within six to twelve months

All five treatment centres reported cases of patient dropout from ART in the last six to twelve months. As shown in Table 1, a total of 232 HIV patients (1.9% of the total number of patients on records in the five TCs) were lost to follow up within a six months' period. TCs suggested various reasons as causes of loss-to-follow-up (Table 3).

## Deaths after dropout (LTFU) from ART

As shown in Figure 1, all TCs reported at least one case of death of the dropout or LTFU cases. A total of 38

Table 1. Total patients on treatment at TCs and LTFU in six months.

Treatment centre	Total (n) on ART	Total (n) LTFU
CNPS Hospital, Essos	6,105 (50.2%)	106 (45.7%)
Djoungolo District Hospital	4,500 (37.0%)	60 (25.8%)
CMA, Elig-Essono	600 (4.9%)	32 (13.8%)
CMA, Mvog-Ada	400 (3.3%)	19 (8.2%)
Hope Services Clinic and Maternity	560 (4.6%)	15 (6.5%)
Total	12,165 (100%)	232 (100%)
Proportion of the total (12,165)		1.9%

Table 2. Total adult and children on treatment at TCs.

Treatment centre	Adults	Children
CNPS Hospital, Essos	5,838 (49.3%)	267 (85.3%)
Djoungolo District Hospital	4,480 (37.8%)	20 (6.4%)
CMA, Elig-Essono	589 (4.9%)	11 (3.5%)
CMA, Mvog-Ada	390 (3.3%)	10 (3.2%)
Hope Services Clinic and Maternity	555 (4.7%)	5 (1.6%)
Total	11,852 (100)	313 (100%)
Proportion of the total (12,165)	97.4%	2.6%

Table 3. Causes of Loss-to-follow-up and proposed strategies by Treatment Centres to improve retention.

Causes of loss-to-follow-up	<ul> <li>int importance of ART and danger of failed adherence.</li> <li>(ii) Patient follow-up with reminder calls and text messages,</li> <li>(iii) Demonstration on the dangers of dropout by patients who have defaulted,</li> <li>(iv) Organize support group meetings to educate patients on importance of regular treatment,</li> </ul>	
<ul> <li>(i) Poor adherence to drugs</li> <li>(ii) Ignorance of importance of adherence to treatment</li> <li>(iii) Poor treatment and adherence counseling at point of motivation</li> <li>(iv) Religious beliefs</li> <li>(v) Stigmatisation</li> <li>(vi) Financial hardship making it hard to get to TC due to distance.</li> <li>(vii) Poor counseling and beliefs of some patients, especially in traditional medicine</li> </ul>		

dropout patients had died.

Patient transfer between treatment centres

All TCs reported at least one case of transfer to and out of their centre (Figure 2). Reasons for transfers were distance from health facility, change of home, nature of job, movement from first to second line treatment, transfer to areas outside Yaounde, patient privacy, overcrowding, closeness to new TC and patient privacy as major reasons. Regarding other forms of support to patients, only CMA Elig-Essono stated good nutritional advice and encouragement of patients to get involved in some form of business to keep busy and distracted as measures. Three of the five TCs stated absence of drugs in warehouse, delay in supply and expiration of drugs as reasons for shortage of ART.

## DISCUSSION

This study shows that both adults and children were treated in the same treatment centres as supported by WHO (2020); Kaiser Family Foundation (2019); UNAIDS (2018b). The higher number of patients (69.4%) being females is indicative of the vulnerability of women to HIV infection and their being proactive and timely in seeking treatment (Brown et al., 2019).

Concerns of high attrition rates throughout the continuum of care from HIV diagnosis, to long-term retention remain (Kathryn et al., 2015; WHO, 2013; Clouse et al., 2013; Charurat et al., 2010; Rosen et al., 2007). Such attrition compromises gains from ART scale-

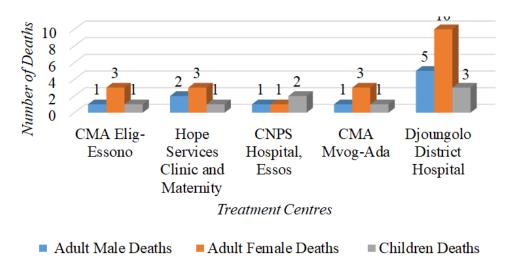


Figure 1. Deaths after dropout from treatment.

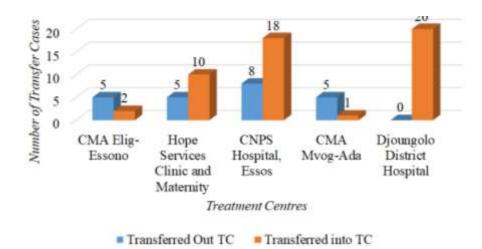


Figure 2. Transfer Cases in and out of Treatment Centres.

up, leading to poorer health outcomes and wastage of limited resources (Clouse et al., 2013; Charurat et al., 2010; Rosen et al., 2007; Tenthani et al., 2014; Matthew and Sydney, 2015; Lessells et al., 2011; Charurat et al., 2010). A prevalence of 4.5% (Wung et al., 2016), and 12,165 patients engaged in treatment in only five centres, is indicative of a successful scale-up programme in Cameroon (Bekolo et al., 2013; Mosoko et al., 2011). Although, LTFU of 1.9% in this study is relatively low, it might be an underestimate due to the fact that only fewer TCs in Yaounde participated, compared to the 33% LTFU reported in a national study by Bekolo et al. (2013). There is need to conduct a study with more TCs to further ascertain the findings in this study.

Adherence to a medication is a dynamic process influenced by many support factors (social support, positive treatment outcomes, and life-long projects) and barriers (medication cost, access to health facilities, transport costs, and fear of stigma and discrimination (Bezabhe et al., 2014). This research provides support to the fact that financial hardship hinders patients from seeking and remaining on treatment as reported by Yehia et al. (2015). Thomas et al. (2007) supported findings regarding stigmatisation and religious beliefs as contributing factors to dropout from treatment. Long distances to health services, direct and indirect costs (travel time, time spent in healthcare facility and informal carers' time) also influence retention in care as supported by WHO (2013). Social determinants such as poverty. work/child care and geographical challenges revealed in this study as contributing factors to poor retention lend weight to similar results by WHO (2013) and Elvin et al. (2010). Such findings are further strengthened by Bezabhe et al. (2014) and WHO (2013). Lack of

education, finances, and long distance to TC reported in this study are corroborated by Brown et al. (2019); Bezabhe et al. (2014); Mbuagbaw et al. (2013); Mbuagbaw et al. (2013); Matthew and Sydney (2010). Thomas et al. (2007) substantiated findings that belief in traditional treatment was found to be one of the major causes of failure to engage and remain in treatment, leading to a continuous surge in viral load (Kaiser Family Foundation, 2019; UNAIDS, 2018a; Benjamin, 2014; WHO, 2013; Clouse et al., 2013; Elvin et al., 2010). Some of the deaths reported in this study are as a result of dropout from treatment when families report but most likely an underestimate as many of such deaths are not reported. Mortality linked to HIV or a result of aggravated comorbidity due to dropout from ART is supported by Kathryn et al. (2015). The consequences of LTFU are poor adherence to ART, leading to immune suppression, regimen failure, emergence of resistant viral strains, and limited future treatment options, further comprising gains from treatment programmes (Bezabhe et al., 2014).

This study offers insights into retention strategies which can complement scale-up measures and reduce LTFU or dropout rates. However, retention is not a one-off event but a continuous process in the continuum of care. Therefore, instituting sustained counseling and education services to overcome stigmatisation, ignorance, as well as financial incentives to overcome financial barriers are crucial for retaining HIV-infected patients within retention metrics. Lifting logistical barriers to HIV care, providing flexible treatment environments, and accelerating linkage to care, are prerequisites to retention and adherence.

# Proposed strategies to improve patient retention in care

Although varied among the treatment centres, all proposed strategies are complementary and should be implemented concurrently. The TCs proposed the following measures to improve patient retention in care:

(i) Community-based sensitisation and awareness on the importance of adherence to treatment be conducted to promote shared responsibility of care to include not only HIV patients but family members and caregivers. Education of family members and communities will tackle stigmatisation and discrimination.

(ii) Organising social support groups and performing sustained proper and intense counselling, encouragement and education of patients to inform and continue to remind them of the importance of adherence to treatment and the dangers of drop out.

(iii) Communication using cell phones and social media (WhatsApp, Facebook etc.) between TCs and patients, families and caregivers should be promoted. A WhatsApp forum that groups together patients will promote inclusive discussion of patients and the opportunity to share experiences among themselves and to know that they are not alone. Although patients enrol at different times, such measures can possibly help them remind each other of treatment dates. In addition to sms and social media reminders, Treatment Centres should go an extra mile to make reminder calls to patients, especially after first absence from refill to ensure that funding for HIV yields expected gains and value for money. However, strict privacy norms and etiquettes must be put in place.

(iv) Experience sharing is important in passing across lessons. Therefore, getting patients who defaulted and later returned to treatment to demonstrate or share their stories could be useful to others who have dropped or are considering doing so.

(v) Use of patient registration software that can send auto reminder messages to patients depending on when they engaged in treatment. This will remind the patient to consistently and regularly go for medications.

(vi) Despite subsidy on ART, associated costs like transportation to TCs is a hindrance. Therefore, establishment of transport vouchers for patients with financial hardship could help to lift financial burden and improve retention in care.

(vii) Regarding patients changing homes or going on transfer, a system of patient transfer and tracking should be established to ensure that patients relocating are automatically connected with the treatment centre nearest to their new home or place.

(viii) Increase human resources and services so that patient reception at TCs is faster so they do have to queue or spend more time.

(ix) TCs should avoid labels, signs or comments that identify patients. This will reduce stigmatisation and discrimination.

(x) Periodically take patients through some psychotherapy to tackle cases of trauma, stress, anxiety, and mood disorder, as well suicide ideation.

(xi) Transfer patients who dropped out and experienced increase in viral load to second line of treatment and follow-up for adherence. Good adherence counselling for 3 to 4 months and submission of patients to another viral load test.

# **CONFLICT OF INTERESTS**

The authors have not declared any conflict of interests.

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