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## ORIGINAL ARTICLE

# Retention in HIV/AIDS Management Services: is it Really Poor? The Case of Yaounde Central Hospital in Cameroon

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## ABSTRACT

**Background:** After consecutively defaulting on their appointments for three months, many HIV positive patients are often reported to have defaulted on their treatment, become lost to follow-up (LTFU), or no longer in care. We sought to determine if retention in HIV/AIDS care and treatment is really poor.

**Methods:** Outcomes of patients with missed clinic appointments and reasons for missing appointments were studied. We sampled adult HIV positive patients on antiretroviral therapy (ART) who by clinic had missed their clinic appointments by more than four weeks between 1997 and 2019 at the HIV Care and Treatment Center (CTC) (Day Hospital) of the Yaoundé Central Hospital. We assumed that patients who missed their clinic appointment also missed some doses of their ART medications. Patients considered LTFU and those who had defaulted for two months were traced by telephone calls and home visits. Reasons for ART discontinuation were recorded for those who stopped or interrupted ART.

**Results:** Of the 1139 patients who were either LTFU or who had defaulted for two months, 247/1139 (22 %) could not be traced. Out of the successfully traced patients, 50 (4%) had died and 798/1139 (70%) were alive and 310/1139 (27%) were on ART of which 35/1139 (3%) had developed informal ways of obtaining ART through clinic personnel. A good number were brought back to and reinitiated on ART after tracking (540/1139 or 47%). Of those known not to be on treatment (ART), 27/1139 (2%) had deliberately stopped ART and 63/1139 (6%) promised to return and took an appointment with CTC psycho-social workers. Major reasons shared for missing clinic appointments were travel out of city (39%), distance from health facility, and financial cost for getting to health facility.

**Conclusion and Global Health Implications:** Despite clinic data showing many patients had missed monthly appointments or were LTFU, we saw that a sizeable amount of such patients were actually in care and on ART. The above findings lead to the suggestion that clinic data used in program performance

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evaluation may not always reflect the true picture retention in care for persons in HIV/AIDS programs at hospital and national levels.

**Key words:** • Lose to follow-up • Patient outcomes • Missed appointments • Cameroon • HIV/AIDS  
• Retention in care

## 1. Introduction

HIV/AIDS care and treatment in Cameroon and many other African countries have improved in recent years. More people are being tested and unlike in the past, positive cases are identified and linked to care and treatment before they develop AIDS. Retaining patients on treatment is key to attaining epidemic control but it is however very challenging. A good number of HIV positive patients on treatment default on treatment plans and become Lost To Follow Up (LTFU). As days go by, the number of LTFUs is on the rise, making it a big challenge for the long-term success of ART programs. However, in relation to the challenge of retaining patients in care, performance might be compounded by several factors some of which might poor health information systems and documentation.

Sub-Saharan Africa, has a number of HIV-infected individuals of up to 5% who are lost both before treatment<sup>1</sup> and after initiating treatment.<sup>2,3,4</sup> Our observation of discrepant relationship between rates of viral suppression for the Day Hospital which was 89% for all available results at the end March 2019 and the 12-months retention rate which was 67% prompted us to plan a review to understand if patients who had defaulted care were really not on care and hence carry out this study through implementation of a patient tracking exercise for patients not in care as per hospital records from October 2018 to March 2019 dubbed "Return to Care Campaign."

### 1.1. Objectives of the Study

The goal of this campaign was to bring back to treatment all HIV positive clients who defaulted and to improve retention. Clients reported as LTFU or having missed their ART refill appointment for more than 28 days were listed and contacted via phone calls and home visits. Specifically, our study focused on the results of the RTC campaign at the treatment center of the Yaounde Central Hospital.

Our objective was to determine if retention in HIV/AIDS care and treatment is really poor. Outcomes of patients with missed clinic appointments and reasons for missing appointments were studied to inform future service delivery for improvement.

## 2. Methods

### 2.1. Study Population and Setting

Yaounde is a cosmopolitan city and the capital of Cameroon. It is the second-largest city after Douala, with an estimated population of 2.5 million people. The HIV outpatient clinic of the Yaounde Central Hospital is the first-ever accredited and reference clinic for HIV/AIDS management in Cameroon. Together with other approved HIV treatment centers, it serves the population of Yaounde. It currently has about 11,000 people living with HIV enrolled in the unit and receives approximately 8,500 to 10,000 of them every month.

### 2.2. Study Design

This was a serial cross-sectional study based on routine data from a patient tracing program at the HIV outpatient clinic of the Yaounde Central Hospital. All patients, enrolled in the HIV clinic of the Yaounde Central Hospital, confirmed to have been LTFU or having missed their ART appointment for more than 28 days between for two quarters: October 2018 to December 2018 and January 2019 to March 2019 were included in our study. We excluded clients lost in a quarter but later returned within the same quarter. Patients were traced by phone and/or home visits. Outcomes from the tracing and the reasons for defaulting were documented. Data collection, data management, and statistical analysis methods were adapted from another study.<sup>6</sup>

### 2.3. Data Collection

The socio-demographic data and contact details of the patients included in the study were obtained from Data Manager (DAMA), proprietary computer

software used in the unit for patient follow-up and drug dispensation, and recorded in an excel sheet. The information was then distributed among trained linkage and retention agents who had two main tasks. The first task was with crosschecking to ensure that clients included had truly missed their refill appointments for more than 28 (defaulters) or greater than 90 days (LTFU). Secondly, attempt to bring them back to care and treatment. This was done by trained psychosocial agents (PSA) who work in the unit and had specific cohort of patients to follow-up and report on if there were challenges. They were all expected to track these patients by calling for up to four times on four different days and paid a home visit to clients they did not bring back to care through a phone call. Home visits were possible because of location plans or descriptions routinely collected in patient records. The date and outcome of each call or home visit were then recorded progressively against each patient's code. The reason for defaulting and the outcome from the tracking exercise were equally recorded. The outcome of tracking was documented as (1) died; (2) transferred out to another facility (either 'official transfer' if the transfer-out letters were available in the patient's file or 'auto-transfer'); (3) on treatment (a patient who has passed to pick medications that same month or missed just two appointments); (4) stopped treatment; (5) LTFU (did not attempt to trace or traced but unable to locate).<sup>6</sup>

#### 2.4. Data Analysis

A descriptive statistical analysis was done using Microsoft Excel version 16. Categorical variables were expressed as frequencies and proportions. In the analysis of the reasons for collecting ARVs from other sources, we included patients that were reported to be self-transferred to other facilities. Patients who self-transferred to other health facilities were included because their experiences provided insight into the challenges faced by ART patients, although they successfully remained in care. Similarly, patients who stopped ART provided insight on their experiences before they stopped.<sup>6</sup>

#### 2.5. Ethical Considerations

The study was approved by the ethics committee of the Yaounde Central Hospital (YCH). Informed

consent was not required as the ethics committee waived the need for patient consent to be part of the study since the study used routine programmatic data and did not include any personal details which could identify patients.

### 3. Results

#### 3.1. Age, Sex and Duration on Art Distribution of Participants

During the period from March 28, 2019, to April 23, 2019, 10,064 adults and children received ART medications through the clinic. Baseline demographic data for this group were collected. The study population was found to be 70% female (798 out of 1139 patients) and 30% male (341 out of 1,139 patients). Ten percent had been on ART for less than a year; 24% had been on ART between 1-3 years, while 66% had been on ART for more than three years. Among the study population, (n=1139), 247(22 %) were LTFU, with the remaining 892 patients found to be continuing active follow-up (Table 1).

#### 3.2. Tracking Outcome

From the campaign, 50 patients were reported dead after calling their family members, 540 patients returned to care after calling them, 63 patients promised to return, 27 patients vehemently said they have stopped treatment, 113 patients were

**Table 1: Socio-demographic characteristics of study participants**

	Male	Female	Total	%
Age distribution	<15	0	0	0
	15-20	2	10	12
	21-30	26	179	205
	31-40	92	288	380
	41-40	129	182	311
	51-60	66	104	170
	61-70	18	28	46
70+	8	7	15	
Duration on ART	< 1 Year	33	79	112
	1-3 Years	93	182	275
	> 3 Years	215	537	752
<b>TOTAL</b>	<b>341</b>	<b>798</b>	<b>1139</b>	<b>100</b>

transferred to other facilities, 31 patients had drugs from other sources. 247 patients were not reached due to either wrong numbers or their phones were switched off (Table 2).

### 3.3 Reasons for Defaulting

Of the 465 patients who gave reasons for defaulting, 181 gave reasons of travel, 53 said the distance to the hospital was the cause of their absence, and 48 said the cost of transportation was the reason for their absence (Table 3).

## 4. Discussion

Our study found out that a proportion (12.6%) of patients initially considered LTFU or missed appointments were actually alive and collecting ART from friends, other hospitals or reserves from previous visits or other sources outside the hospital, which suggest the need for both hospital-based retention interventions and improvements in data quality. This is in line with studies by a study done in 2013.<sup>7,8</sup> The most frequent reasons for defaulting were traveling, cost of services and cost of transportation. This was in line with results from a prior study<sup>9</sup>.

In Cameroon, national policy provides an opportunity for all ART patients to collect an emergency supply of ARVs from any other ART hospitals so as to help address patient travel needs. However, due to stock tension of some protocols

at sometimes, this policy is hardly respected. In addition, the waiting time at the pharmacy (3-5 hours) and delay to renew medication refill orders at the hospital were major reasons patients gave for missing appointments. The Yaounde Central Hospital is the biggest treatment center for HIV in the entire country receiving on average 500 patients per day and has the highest specialized units and thus many patients prefer coming there, thereby making waiting time increase. Although this time of waiting was lower than the average time reported in other similar studies.<sup>10,11</sup>

We had more than 6% of patients that were reported to have missed appointments whereas they were misclassifications; thus, showing that it was a documentation problem. There is an urgent need for health facilities to improve communication between facilities and transfers between sites. There is also need to properly document transferred patients as about 10% of those successfully traced in this study were taking their treatment from other facilities while being documented as LTFU in their previous health facility. There is also a great need to set up data linkages through which information of patients that are transferred to other facilities could be shared. This is in line with another study.<sup>12,13</sup>

### 4.1. Limitation and Recommendation

The limitation of this study was lack of complete information in some patient files. The researchers

**Table 2: Tracking outcome among study participants**

Tracking outcome	Tracking outcome			
	1 Oct-Dec 2018	2 Jan-March 2019	Grand total	%
Deceased	35	15	50	4
Returned to care after tracking	442	98	540	47
Promised to return	39	24	63	6
Stopped ART	22	5	27	2
Other (LTFU)	180	67	247	22
On ART: No missed appointment, not properly documented	15	13	28	2
On ART: Officially Transferred out	38	10	48	4
On ART: Silent transfer	52	13	65	6
On ART: Received ARV from another facility	3	2	5	0.1
On ART: Still has ARV from previous visits	17	14	31	3
On ART: Received ARV from an informal source	23	12	35	3
Grand total	866	273	1139	100

**Table 3: Reasons for defaulting on treatment plans**

Reasons for defaulting	Total (N)	Percentage
Stigma	2	0
Inconvenient hours	27	6
Travel	181	39
Feels healthy	6	1
Long distance	53	11
High cost of transportation	48	10
Side effects of ARVs	5	1
High cost of services	10	2
Bad staff attitude	9	2
Traditional beliefs	1	0
Religion	7	2
Status denial	3	1
Others	113	24
Grand total	465	100

believe that bringing ARVs to the community through community dispensation may provide additional benefits for patients who may not have money to come to the hospital or who stay far from the hospital. This may also, reduce waiting time in the hospital as the pharmacy will be decongested. We recommend further studies on waiting times and reasons for defaulting with larger sample sizes.

## 5. Conclusion and Global Health Implications

Despite clinic data showing many patients had missed monthly appointments or were LTFU, we see that a sizeable amount of such patients were actually in care and on ART. The above findings lead to the suggestion that clinic data used in program performance evaluation may not always reflect the true picture retention in care for persons in HIV/AIDS programs at hospital and national levels and therefore it is recommended for program to make adjustments to retention in care estimates to account for actual treatment gaps and non-interrupted therapy. In addition, our findings show it is feasible to track and bring “lost” patients back to care through very cost-effective and simple methods. In this study, 47% of patients LTFU or who missed appointment were able to be brought back to care. A multifaceted

response to address problems related to cost of services (travel cost and services) and implementing differentiated care modalities like extending hospital hours, multi-month dispensation of medications for stable patients through multi-months or using community antiretroviral therapy dispensation modalities and strengthening health information systems will help address many of the challenges and ameliorate retention in care and improve attainment of the UNAIDS “90-90-90” goals.

## Compliance with Ethical Standards

**Competing Interests:** The authors declare that they have no competing interest; **Financial Disclosure:** None; **Funding/Support:** There was no funding for this study. **Ethics Approval:** Approval for the study was obtained from the ethics committee of the Yaounde Central Hospital (YCH). Consent for tracing was obtained from the patients during ART registration according to routine clinic procedures. Informed consent was not required as

### Key Messages

- Patients considered to be lost to follow-up (LTFU) or have missed appointments make up a reasonable proportion of the actual patient outcomes; the different categories of LTFU included a large proportion of patients with uninterrupted therapy and treatment differences which may give a false retention estimate at both the hospital and national levels.
- LTFU estimates could account for the real treatment differences and non-interruption of treatment.
- Health providers can potentially expand hospital working hours, increase drug allocations for stable patients through multi-months’ prescriptions, or do more work to decentralize ARV distribution locations to communities through community-based organizations (CBOs) to prevent further LTFU and missed appointments.
- Hospital staff should improve the quality of clinic documents to avoid declaring patients LTFU or missed appointments when they are actually in treatment.

the ethics committees waived the need for patient consent to be involved in the study. **Acknowledgments:** We are grateful to the directorate of the Yaounde Central Hospital for allowing us to have access to the data. We will like to also acknowledge the technical support the health facility received through CDC (Cameroon) through conception of data tool and mentorship.

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