Retention and loss to follow-up in antiretroviral treatment programmes in southeast Nigeria

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Background: This study generated new information about the outcomes of patients enrolled in antiretroviral treatment programmes, as well as the true outcomes of those lost to follow-up (LTF).

Methods: Anonymized data were collected for patients enrolled over a 12-month period from two programmes (public and private) in southeast Nigeria. Estimates of retention, LTF, mortality and transfers were computed. All LTF enrollees (defined as patients who had missed three scheduled visits) whose contact information met pre-defined criteria were traced.

Results: A total of 481 (public) and 553 (private) records were included. Median duration of follow-up was about 14 months. Cumulative retention and LTF proportions were 66.5 and 32.8% (public), and 82.6 and 11.0% (private) respectively. LTF rates at third, sixth, ninth and twelfth months were 7.5, 19.3, 25.4 and 29.6% respectively (public), and 4.1, 7.1, 9.0 and 10.0% (private). LTF was higher among males, patients with CD4⁺ cell count ≤ 200 and public programme enrollees. For the public facility, 56.7% of 104 traceable patients were dead and 38.8% were alive; the figures were 34.2 and 60.5% of 46 patients respectively for the private. Most deaths had occurred by the third month.

Conclusion: Not all patients enrolled for treatment were retained. Though some died, many were LTF, lived within the community, and could develop and transmit resistant viral strains. Most traced patients were dead by the third month and poor contact information limited the effectiveness of tracing. Antiretroviral treatment programmes need to improve documentation processes and develop and implement tracing strategies.

Keywords: Antiretroviral therapy, HIV, Retention, Loss-to-follow up, Nigeria

Introduction

Nigeria in December 2005 scaled up its antiretroviral programme with the aim of providing antiretroviral drugs at no cost to about 250 000 HIV-positive residents, and by 2006 had established 74 antiretroviral treatment (ART) centers across the country. The reported numbers of people receiving treatment by September 2007 and 2010 were 145 392 and 359 181 respectively, and UNAIDS estimated a coverage of 26% in 2007, and 26% in 2010.¹⁻⁴

Patients on ART might be alive and on treatment in a facility, lost to follow-up (LTF), dead or still in care but stopped treatment.⁵⁻⁹ Those designated as

LTF may be alive, dead or truly LTF if all efforts at reaching them using available contact information have failed. For LTF patients who are alive, some might be receiving drugs in the same facility and may even re-enroll as new patients; others for some reason discontinue treatment. Dead patients may have died soon after their last visit while some may have lived longer.

Following 9 months of follow-up of patients in 13 sub-Saharan Africa countries (not including Nigeria), Rosen *et al.*⁸ showed retention rates ranging from 46 to 85%. High rates of retention (77%) were also noted in programmes run by Médecins Sans Frontières in 11 countries in Africa,⁵ and in 66 public health facilities in Malawi (73%).¹⁰

Variations in the pattern of LTF usually depend on the structure of the programme, including the

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extent to which patients who default from treatment are followed up.⁸ Attrition is mainly accounted for by LTF patients. Where patient tracing is effective, attrition rate due to LTF might be reduced.^{10–12} In 33 patient cohorts studied in sub-Saharan Africa, LTF accounted for 56% of attrition, and death 40%.⁸ Some living patients stop treatment, but the figure is usually below 1.5%.^{10,13}

A number of studies have traced LTF patients in ART programmes in sub-Saharan Africa.^{7,9} These studies have shown high mortality rates among them, early occurrence of deaths and failure of tracing effort due to incorrect or incomplete addresses and missing telephone numbers. However, there is no information about such patients in Nigeria, a country that has the third highest number of persons receiving ART in the world, and where over 3 million people are infected with HIV/AIDS.¹⁴

A major implication of LTF and the need for defaulter tracing is the increased risk of development of resistance to drugs.^{15–17} Alternative treatments that may have to be used are not easily accessible, are more expensive, have significant side effects and may fail. Furthermore, resistant strains of HIV could develop and be transmitted, thus creating an impediment to the effectiveness of future treatment options for individuals who are newly infected. Such negative outcomes have been noted for diseases where patient adherence is a challenge.^{18,19}

Knowing rates of retention and LTF will provide a more valid estimate of patients who are on ART and enable better planning and use of resources. Otherwise, available figures, which are usually updated records of new enrolment, are likely to be an overestimate of actual number of individuals on ART. Poor data will impact negatively on estimated resource needs and promote inefficiencies in resource allocation.

This study aimed at generating new knowledge about the pattern of retention and attrition as well as the outcomes of LTF patients in ART programmes in southeast Nigeria to enable better definition of those actually receiving treatment, and the need to improve on strategies that promote patient retention.

Materials and Methods

Study Area

This study was carried out in Enugu state, southeast Nigeria between June and December 2008. The state comprises 17 local government areas (LGAs) and has a total population of 3 257 298 people.²⁰ The state serves as the heart of the southeast region of the country and the state capitals of the other four states of the region are within a travel distance of 200 km. The major occupations are public service, farming and petty trading.

Study site and programme description

Two hospitals, the University of Nigeria Teaching Hospital, a public facility, and Annunciation Hospital (a not-for-profit private facility) were purposively selected for the study, being the only facilities in the state that had offered ART for more than 1 year as at the time of commencing the study. The University of Nigeria Teaching Hospital ART programme, supported by the Federal Ministry of Health with funding from the Global Fund, started in 2002 with provision of free drugs to patients commencing in 2006. However, patients had to pay for some of their initial laboratory tests. The private facility programme started in 2006 and provided drugs and laboratory tests free to patients. The programme is funded by AIDS Relief, a provider for PEPFAR initiative administered through the School of Medicine, University of Maryland. Both hospitals receive patients from Enugu (the primary catchment area) as well as from nearby parts of southeast Nigeria and there was no facility access charge for patients to register in both programmes.

Patients individually make a choice of the facility where they seek care. In both programmes, eligible patients are enrolled after undergoing pre-treatment adherence counselling, and are subsequently placed on three drugs — lamivudine (3TC), nevirapine (NVP) and zidovudine (AZT) as the preferred first line course. Enrollees are required to make monthly visits to the facility for drug pick-up. Information regarding patient's residential address as well as the name and address of a patient-recommended contact person is collected. Additionally, the private-run programme collects phone numbers of the patient and a contact person and is active in using this to reach patients or the contact person when a patient defaults.

Study design and procedure

Records included for the study were those for patients who enrolled from January to December 2007 in both facilities. Anonymized data (based on facility enrollment numbers) was collected from hospital records of patients by trained field workers. Data were collected on patient's socio-demographic characteristics, baseline CD4⁺ cell count and visits to facility for drug pick-up to enable assessment of outcomes of interest. The data sheet used was pretested at both facilities to ensure its usefulness for elicitation of variables of interest. Facility registers of patient visits were examined to determine those no longer attending and those known to be dead, and we ensured that this corresponded with documentation in patient registers.

A list of all the patients LTF (defined as a patient who has missed three clinic visits or medication pick-up)^{5,7,9} was compiled and used for tracing. A data

sheet was used to obtain information on status of patient from enrollees LTF or a close relative where patient was unavailable. All recorded contact details of patients LTF were retrieved from patients' folders and assessed for tracing. The details included patient's residential address, the name and contact address of next of kin, and telephone numbers of the patient and next of kin where available. A patient from an urban area was judged untraceable and so excluded if the contact detail did not specify the house address of the patient or the address or phone number of his next of kin. On the other hand, a patient from a rural area was judged untraceable and excluded if his contact details did not have the name of his village or his phone number, or the name and village or phone number of his next of kin or contact person. Patients with addresses outside the southeast region of the country were described as 'other' and excluded. The field workers interviewed all patients found on tracing and willing to grant an informal interview. The household caregiver was interviewed if the patient was incapacitated. Information on patient's financial and social support system, and access to and perceptions about ART services was obtained through an informal discussion of patient's experiences and practices since the last clinic visit. Discussions were manually recorded.

Definition of key variables used for the study

We used definitions common in the literature to categorize patients,^{8,9} namely (1) alive and on treatment in facility; (2) alive and on treatment in another facility; (3) LTF; (4) dead; and (5) still on care but stopped treatment. Patients categorized as 'alive and on treatment' were enrollees who were still receiving treatment. The second group (transfers) included those who had moved to another facility with the knowledge of the health provider. These two groups were defined as 'retained'.⁸ 'LTF' comprised patients who missed three scheduled monthly clinic visits or medication pick-ups.^{5,7,9} All those recorded as dead in the patient registers or facility records were categorized as 'dead'. A patient was defined as 'truly LTF' if all efforts at reaching him using available contact information failed.

Data analysis

Data analysis computed outcomes based on the definitions above. LTF was analyzed using two approaches. The first was based on cumulative assessment of status of the studied cohort. This commonly used approach provided the count of LTF patients for tracing, but is limited in that it cannot be used to determine at what time an enrollee is more likely to need specific interventions to prevent default. The second approach used in this study was based on

the Kaplan Meier survival analysis technique (with LTF as outcome of interest) to determine LTF rates in a 'time to event' manner. Using proportionate hazards regression analysis, we explored whether LTF was influenced by a patient's gender, age, urban/rural LGA of residence, CD4⁺ cell count or health facility of enrollment. The proportional hazard model was developed in a forward stepwise manner with the key independent variable 'facility' added as the last variable. For the qualitative data, emphasis was placed on the interpretation as well as the description of the actual statements of the participants. Manual content analysis was employed for the data. The quotes presented here were selected to illustrate themes articulated in various ways by respondents.

Results

A total of 488 and 553 patients were enrolled in the public and private facilities respectively. Seven records in the public programme were grossly deficient of needed information while two enrollees in the private programme did not commence treatment at all. These were excluded from the analysis. A total of 481 and 553 records were thus used for analysis. The median durations of follow-up in the public and private programmes were 13.7 months (inter-quartile range=10.7–16.0) and 13.8 months (inter-quartile range=11.8–16.7) respectively. The mean baseline CD4⁺ cell count was 131.1 [standard deviation (SD)=84.6] and 203.3 (SD=141.7) for public and private patients respectively.

Socio-demographic characteristics of respondents

The mean age of enrollees in the public facility was 37.1 years (SD=9.3). Most were female (61.1%), lived in a rural area (53.6%), were married (51.6%), and were mostly petty traders (39.0%) and artisans (19.2%) (Table 1). For the private facility, the mean age of enrollees was 32.0 years (SD=12.7). Most of them were equally female (67.5%), lived in the urban area (67.7%), were married (45.8%) and were mostly petty traders (29.3%) and civil servants (16.6%).

Cumulative assessment of status of patient for the studied cohort

Retention of patients in the public facility was 66.5% (Table 2) while the proportion LTF was 32.8%. Only two patients (0.4) were recorded as dead while one (0.2) was transferred out. Retention in the private facility cohort was 82.6% while 11.0% were LTF. Thirty-five patients (6.3%) were recorded as dead. Retention was higher in the private facility (chi-square: 35.8; $P<0.001$), while the proportion of LTF patients was significantly lower (chi-square: 73.4; $P<0.001$).

Table 1 Socio-demographic characteristics of respondents

	Public (n=481) Frequency (%)	Private (n=553) Frequency (%)
Sex		
Male	187 (38.9)	180 (32.5)
Female	294 (61.1)	373 (67.5)
Mean age (standard deviation)		
Male	40.0 (8.4)	34.8 (14.9)
Female	35.2 (9.5)	30.7 (11.3)
Total	37.1 (9.3)	32.0 (12.7)
Place of residence		
Urban	223 (46.4)	355 (67.7)
Rural	258 (53.6)	169 (32.3)
Ethnic group		
Ibo	476 (99.6)	541 (97.8)
Hausa	0 (0)	6 (1.1)
Yoruba	0 (0)	1 (0.2)
Other	2 (0.4)	5 (0.9)
Marital status		
Married	246 (51.6)	196 (45.8)
Single	133 (27.9)	152 (35.5)
Widowed	84 (17.6)	69 (16.1)
Separated/divorced	14 (2.9)	11 (2.6)
Occupation		
Unemployed	36 (7.7)	70 (15.5)
Student/learner	40 (8.5)	46 (10.2)
Farmer	39 (8.3)	27 (6.0)
Artisan	90 (19.2)	57 (12.6)
Petty trader	183 (39.0)	132 (29.3)
Civil servant	47 (10.0)	75 (16.6)
Employed in private firm	3 (0.6)	15 (3.3)
Small to mid-scale business	2 (0.4)	7 (1.6)
Teacher	27 (5.6)	22 (4.9)
Other	2 (0.4)	0

Examination of LTF rates using kaplan meier survival analysis

The cumulative rates of LTF at third, sixth, ninth and twelfth months from the time when patients were individually enrolled to commence ART were 7.5, 19.3, 25.4 and 29.6% respectively for those in the public facility, and 4.1, 7.1, 9.0 and 10.0% respectively for those in the private facility (Table 2). LTF rates increased at a faster pace for the public facility after the third month in care. There is very strong evidence of a difference in LTF rates (log rank test

for equality of survival function between public and private facilities: chi-square=59.8; $P<0.0001$).

Determinants of loss to follow-up

As shown in Table 3, the risk of LTF was 47% higher among males compared to females [$P=0.007$; 95% confidence interval (CI): 1.11–1.95]. The risk was 31% lower among those with CD4⁺ cell count >200 ($P=0.029$; 95%CI: 0.49–0.96), and 2.9 times as much for patients in the public facility compared to those in the private one ($P<0.001$; 95%CI: 2.16–4.00). Age and LGA of residence were not significant predictors of LTF.

Assessment of patient's contact details and outcome of tracing

Of the 158 LTF patients in the public facility, 104 (65.8%) were traceable and 41 (26%) were not, while 13 (8.2%) were considered as 'others'. On the other hand, 46 (75.4%) of 61 LTF patients from the private facility were traceable while 11 (18.0%) and 4 (6.6%) were considered as not traceable and 'others' respectively. The non-traceable addresses were poorly recorded. All 104 and 46 patients from the public and private facilities were traced, of which 67 (64.4%) and 38 (82.6%) respectively were found.

Outcome status of patients LTF and successfully traced

For the public facility, most (38; 56.7%) were dead; 71.1% had died by the third month after their last clinic visit (Table 4). Another 39% of patients traced successfully were still alive, of which 6 (23.1%) had stopped treatment, 10 (38.5%) were on ART in a different facility and 3 (11.5%) in the same facility, having registered with new names. Most patients (23; 60.5%) from the private facility found on tracing were still alive; 52.2% of them had stopped treatment while 21.7% were on ART in a different clinic. However, 13 (34.2%) were dead and 69.2% had died by the third month after their last clinic visit. For the public facilities, those who were still alive seemed to be more of rural dwellers, females and younger patients when compared to the rest of the patients, and less likely to be females, younger patients and those with CD4⁺

Table 2 Cumulative outcomes and estimates of loss to follow-up

Cumulative proportions of patient cohort studied Status	Public (n=481) Frequency (%)	Private (n=553) Frequency (%)
Retained	320 (66.5)	457 (82.6)
Lost to follow-up	158 (32.8)	61 (11.0)
Dead	2 (0.4)	35 (6.3)
Transferred	1 (0.2)	0
Patient stopped antiretroviral treatment	0	0
Probability estimates for loss to follow-up by facility using Kaplan Meier approach		
Month	Rate (95% confidence interval)	Rate (95% confidence interval)
3	0.075 (0.055–0.102)	0.041 (0.028–0.062)
6	0.193 (0.161–0.102)	0.071 (0.052–0.096)
9	0.254 (0.218–0.296)	0.090 (0.069–0.118)
12	0.296 (0.258–0.340)	0.100 (0.078–0.128)

Table 3 Determinants of loss to follow-up

Variable	Hazard ratio		Standard error	P	95% confidence interval
	Crude	Adjusted			
Sex (male)	1.513	1.470	0.212	0.007	1.108–1.950
Age (≥ 35 years)	1.198	0.932	0.134	0.629	0.704–1.236
Local government area (urban)	0.667	0.821	0.114	0.155	0.626–1.077
CD4 ⁺ cell count (>200)	0.520	0.690	0.117	0.029	0.494–0.961
Facility (public)	3.303	2.938	0.464	<0.001	2.156–4.004

cell count >200 for the private facility. However, none of the observed differences in both facilities was significant.

Qualitative findings

Twelve patients who were alive and found on tracing agreed to be interviewed. One had moved to a new facility because many people living in her street worked in the former one. One patient who had restarted treatment in the same facility declined to answer whether she did so with the same name. The most common reason given for stopping treatment was that patient had switched to alternative options, the aim being to obtain cure. The options included use of herbal medicine and visiting a prayer house. One patient however indicated that she just decided to stop as she could not bear the burden of taking drugs all her life. Another patient stopped because he had an accident which led to a depletion of his wealth. For two other patients, the inability to restart treatment after defaulting was related to limited social support and fear of being reprimanded by programme staff. According to these patients,

I stopped treatment for some time to know how I can stay without the drugs. The workers are friendly to me. I came to a point that I became strong and I decided to stay back. However, in recent times I wanted to start again but I am constrained at present. My brother that used to help me financially has not been in town for some time. On my part, I am no longer working since I discovered the sickness. However, I will make effort to come next month. I am very happy that you people came to see me. (Patient A)

I have always thought about starting treatment again but each time, I become afraid of the reactions from the workers there. They are going to scold me real hard and I don't know how to face them. (Patient B)

Some people listed as contact persons were unwilling to admit knowledge of the patient who gave their name as contact person. Someone whose name correctly appeared on the list as a contact person resident in the same house as the patient in an address found on tracing completely denied knowledge of the patient and insisted that the address was incorrect. In another instance in a rural area, though villagers knew a certain name and provided correct guidance for the address, the person found there whose name

Table 4 Outcome status for patients found on tracing

Variable	Public	Private
	Frequency (%)	Frequency (%)
Status		
Dead	38 (56.7)	13 (34.2)
Alive	26 (38.8)	23 (60.5)
Do not know	3 (4.5)	2 (5.3)
Total	67 (100)	38 (100)
Time of death of dead patients after last visit		
0–1 month	18 (47.4)	5 (38.5)
0–3 months	27 (71.1)	9 (69.2)
0–6 months	32 (84.2)	9 (69.2)
0–15 months	38 (100)	13 (100)
Mean (standard deviation)	3.18 (3.8)	4.1 (4.4)
Status of living patients		
On ART in the same facility	3 (11.5)	1 (4.3)
On ART in different facilities	10 (38.5)	5 (21.7)
Stopped treatment	6 (23.1)	12 (52.2)
Refused to answer	7 (26.9)	7 (21.7)
Characteristics of living patients: stopped drugs <i>n</i> (%) / others <i>n</i> (%)		
Local government area (rural)	5 (83.3) / 10 (50)	4 (33.3) / 2 (18.2)
Gender (female)	5 (83.3) / 11 (55)	7 (58.3) / 8 (72.7)
Age (<35 years)	4 (66.7) / 11 (55)	5 (41.7) / 7 (63.6)
CD4 ⁺ cell count (≤ 200)	4 (66.7) / 14 (70)	9 (75) / 9 (81.8)
Marital (married)	3 (50) / 10 (50)	6 (50) / 5 (45.5)

was also correct as a next of kin denied any knowledge of the patient. In another incident, a lady who later admitted being the daughter of a patient that was already dead later remarked that her earlier unwillingness was because two people who alleged that they lent money to her dead mother had come several times to ask her to refund the loans.

On the other hand, for an elderly woman who identified herself as the mother of the patient who was found to be dead, the visit seemed very comforting to her. According to her,

Do you mean that you came all the way from Enugu just to look for him because you have not been seeing him? God will bless you my children.

Discussion

Retention of patients on ART was found to moderate in this study especially in the public facility where almost all patients who were not retained were LTF. At cohort proportions of 66.5% and a significantly higher 82.6% in the public and private-run facilities respectively, the programmes could be said to be losing many patients who otherwise would have been on treatment. Rosen *et al.*⁸ reported a similar range of retention rates of 46–85% for the worst and best programmes in sub-Saharan African countries (not including Nigeria), and more specifically a retention of 73% of enrolled patients in public facilities.⁸

There could be arguments about the differences between retention in care and facility retention. Retention in care includes transfers while retention in facility does not. In our study, only one patient was transferred meaning that the later approximates the former. Silent movement of patients also occurred as we noticed among LTF patients. A few had even re-registered in the same facility. While such patients are still receiving ART, the undocumented movement and its consequences on efficient use of limited resources present a challenge to delivery programmes.

The critical problem with LTF patients is that such individuals are not ART naïve. The more the number of such patients, the more the opportunities for development and transmission of drug-resistant strains of HIV. At a median period of follow-up of 14 months, LTF of nearly a third of enrollees in the public facility could be considered quite significant, and the figure is similar to those from studies of similar duration of follow-up in Cameroon,²¹ Kenya,²² and Uganda.²³ On the other hand, the proportions for the private-run programme (11%) could be considered relatively lower than the above, and lower also when compared with 22% in Cameroon.²⁴

Among socio-demographic and clinical characteristics examined, we found that sex and CD4⁺ cell count were important predictors of LTF. Patients with lower CD4⁺ cell count are usually sicker, were

more in the public facility where mean cell count was much less than in the public facility and recording was poorer. These patients may die earlier with deaths not recorded as well. Our finding of higher rates of LTF among men is similar to findings elsewhere.²⁵ Health service use is generally known to be poorer among males. It is possible that they present when they are sicker or are less willing to give contact details, and therefore accounted for the greater proportion of those who, whether living or dead, were LTF. Nonetheless, the reason underpinning the greater rate of LTF among males needs documentation.

Patients in the private programme were significantly less likely to be LTF. The difficulty with facility determinants of loss to follow-up is how to disentangle the specific ones that need attention. One however that is noted in this study is the depth of information recorded about the patients and quite importantly their relation/next of kin, the use of appropriate information systems to flag details of defaulting patients at defined time intervals, and the vigorous approach to making contact with such patients at defined time intervals. These three systems were in operation in the private-run facility. In addition, the private-run programme was better with recording of mortalities, which could be a result of better defaulter tracing. Public outpatient clinics on the other hand are known to be poor sources of vital statistics data,²⁶ and the paucity of mortality registries in Nigeria and low interest in registering deaths among citizens^{27,28} further worsen their ability to keep records of mortalities.

The widest margins for LTF for both programmes were noted between the third and sixth months from treatment signifying that these months are critical to maintaining patients in care. Variations noted between the two programmes was such that the rate was about twice higher in the public facility at the third month, but nearly three times higher at the sixth month, reflecting the stronger approaches employed to trace patients. A second reason might be that patients drop out because of the cost of laboratory investigations requested at this period in the public facility. Catastrophic expenditure has been reported by some authors among the same study population.²⁹ and provision of free laboratory services may reduce default at this time.

Mortality among patients LTF in both programmes was considerably high, as over two-thirds of the deaths had occurred by the end of the third month when by definition, patients are declared to be LTF. This finding suggests that where patient tracing is insufficient, significant mortalities among enrollees are undocumented. One can infer that facility data from programmes with minimal tracing activity

would be an invalid source of estimates of mortality rates among patients on ART. It also highlights the need for improvement in tracing and documentation of information from tracing efforts.

Given the finding of high mortality by the third month of last visit, a critical question for programme implementation should be when the appropriate time to begin patient tracing is. Many programmes declare a patient LTF 3 months after his last clinic visit. Our findings suggest that tracing patients earlier than this time would be more beneficial to the patients if retention is truly desired, since most are dead by the third month. However, when a decision is made to trace defaulters, an important issue that arises is whether patient contact details are sufficient to enable this and avoid waste of resources, and the willingness of patients/relations to give information. This study found that contact details of about a third and fifth of patients and/or next of kin in the public and private-run programmes respectively were insufficient or incorrect. The unwillingness to provide information could be due to the stigma still attached to the illness or a sense of insecurity, which occurs in societies with significant crime incidents. Very recently, concerns about sustainability of ART programmes in view of the current economic crises have led to calls for more efficient use of limited resource.³⁰ Programme officers need to be sure that the reasons for requesting details of a contact person are well explained to and collected from patients. In addition, detailed information needs to be collected about patient contact persons since if the patient is dead, only someone else can provide information about him/her. It is worth stating that collecting better information, and making contact earlier with defaulting patients would be considered approaches at improving efficiency of programmes and thus better use of limited resources. Use of electronic patient record software in health facilities is common in many developed countries. They offer opportunities for collection of important information for particular groups of patients while also ensuring that relevant information is not skipped. Their use in the study area is still quite rudimentary and presents opportunities for intervention to improve patient care and tracing.

A significant proportion of LTF patients were still alive with at least half of them not receiving treatment anymore. Additionally, over a third of dead ones lived at least 3 months after default. Collectively, these patients represented a significant population of individuals who were not ART naïve and not on any form of care. Discontinuation of treatment is considered more dangerous than periodic adherence.³¹ Consequences would include the development of drug resistance, and transmission of resistant strains of HIV to family caregivers and

social contacts. Moreover, HIV develops resistance to antiretroviral drugs faster than the tubercle bacillus does to antibiotics.³² To the extent that family members assume responsibility for care and support of a patient in the advanced or terminal stage of AIDS, the potential for transmission of HIV and even the resistant strains is considerable.

The responses of LTF patients found alive provide some insight about reasons for default. When a patient is not well informed, when he lacks social support and when he is unsure of the attitude of programme personnel, he could decide not to continue treatment. Making contact with such patients might provide just the right motivation for them to continue with care.

Limitations of the study

A number of limitations might affect the generalizability of the study findings. Disease stage and co-morbidities was inconsistently recorded and would have provided a more comprehensive assessment of patient's clinical status and co-morbidities than CD4⁺ cell count. Some of the data from entries made in patient records and clinic visit registers by programme personnel could be incorrect or incomplete. Addresses may be incorrectly entered and information about patients who were excluded because of such errors may have helped provide better estimates of outcomes. However, for poor records, we cross-checked information in patient folders with that in the programme registers. Individuals of higher socio-economic status could preferentially use private facilities, the non-profit nature of the private facility and the fact that laboratory services were free meant that they are likely to attract poor patients as well unlike the case with for-profit private facilities. Given this situation, examination of influence of socio-economic status on loss to follow-up rates could not be done because of our use of secondary data, which did not include more indicative information for such analysis. Ethical considerations (about disclosures) meant that our demand for information related to outcome was limited where householders were unwilling to provide information about patients' status. This meant that information about their status was unknown and they accounted for the nine patients presented as 'do not know' and 'refused to answer'. It would be apt to carry out more interviews with patients found on tracing. Our report was from few patients for two reasons. A number of those found were ill and could not face such interviews, and a number of patients were unwilling to discuss their situation within their homes. Despite this limitation, the information presented represents a range of views that would serve as a guide for more targeted and larger surveys, and

the above two challenges should be anticipated in such a survey.

Conclusions and implications

This study provides new knowledge about retention, magnitude of LTF and the outcomes of those LTF in ART programmes in southeast Nigeria. With the exclusion of patients known to be dead, not all enrolled patients are retained. LTF was higher among males, patients with CD4⁺ cell count ≤ 200 and those enrolled in the public facility. The study has documented that many LTF patients are alive and the fact that they live within communities increases the risk of the emergence of drug-resistant viral strains. Efforts at primarily reducing LTF, and tracing those who are lost are worthwhile. Such efforts may include simple and cost-effective approaches that can be built into programme costs. Following patients up with telephone or postal reminders or both can be done and may be both socially acceptable and economically rational. Studies that examine such innovations in the study area are needed.

For most LTF patients that subsequently die, mortality occurs before the third month when they are declared LTF by definition and become eligible for tracing. If tracing is done at all — and this should be considered an ethical and moral obligation — it should be done at periods earlier than the third month. Finally, information systems to ensure that patients are kept in care (in terms of patient contact details) are very poor and this can negatively affect outcomes of patients, defaulter tracing and even efficient resource allocation for ART programmes. Patient outcomes are better when a programme has better information not just about patients, but also a contact person referenced by the patient.

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