Patients who return to care after tracking remain at high risk of attrition: experience from a large HIV clinic, Uganda

A Nakiwogga-Muwanga1, J Musaazi1, E Katabira2, W Worodria2, S Alamo Talisuna3 and R Colebunders4,5

Abstract
We determined the retention rate of patients infected with HIV who resumed care after being tracked at the Infectious Diseases Clinic (IDC) in Kampala, Uganda. Between April 2011 and September 2013, patients who missed their clinic appointment for 8–90 days were tracked, and those who returned to the clinic within 120 days were followed up. The proportion of patients retained among tracked patients, and those who resumed care before tracking started was compared. At 18 months of follow up, 33 (39%) of the tracked patients and 72 (61%) of those who had resumed care before tracking started were retained in care. The most important cause of attrition among the traceable was self-transfer to another clinic (38 [73%] patients), whereas among those who resumed care before tracking was loss to follow up (LTFU) (32 [71%] patients). Tracked patients who resume care following a missed appointment are at high risk of attrition. To increase retention, antiretroviral therapy clinics need to adopt a chronic care model which takes into consideration patients’ changing needs and their preference for self-management.

Keywords
HIV, AIDS, treatment, tracking, antiretroviral therapy, missed appointment, resuming care, patients’ retention, risk of attrition, loss to follow up, resource-limited setting, Uganda

Introduction
Previous studies have shown that many patients with HIV infection who miss appointments may resume care after tracking.1–3 Such patients might resume antiretroviral therapy (ART)4–7 but others may get lost again. The retention rate of patients who re-engage into care after a missed appointment is unknown. In this study, performed at the Infectious Diseases Clinic (IDC) in Kampala Uganda, we followed two patient groups who returned to care after a missed appointment for 18 months: patients who were tracked and those who resumed care before tracking started.

Materials and methods
Study setting
The IDC is the clinic of the Infectious Disease Institute (IDI), Makerere University College of Health Sciences. It is located at the Mulago hospital campus, the main national referral hospital in Uganda. The IDC has been providing free antiretroviral (ARV) drugs to eligible HIV-positive patients since 2002.8 Daily, over 400 patients infected with HIV receive care at the IDC, two-thirds of whom are on ART.
visit the IDC on a monthly basis for a clinical assessment by doctors/nurses, or for drug refills through Pharmacy-only Refill Program (PRP). Every six months, a CD4 lymphocyte count is performed. Patient tracking using either the patients’ phone contact, or a home visit became the standard of care at IDI in 2009.

**Study design**

In January 2011, using the information from the IDC data base, we identified 4582 HIV-positive patients aged 18 years and above who had visited the clinic within 90 days prior to the study period, and had a planned return visit within the next 30 days. These formed a pool of patients from which the study patients were selected. The identification numbers of 4582 patients were arranged in ascending order. Using systematic random sampling with an interval of 4, we selected 1145 (25%) patients in a prospective study. Patients who missed their appointments for 8–90 days were tracked, and all those who returned to the IDC within 120 days were followed up. From April 2011 to September 2013, we used information from the IDC database to determine the patient status every 6 months for 18 months.

**Data collection**

Information was extracted by trained research assistants from two sources: the IDC database and the medical notes. The IDC database was managed by the data manager; the medical notes were completed by doctors/nurses. Data were double-entered into EPIDATA version 3.1 statistical software (Epi-data, Norway, 2006), cleaned, edited, coded, and exported to STATA version 11 (Stata Corp, College Station, TX, USA) statistical software for anonymous analysis.

**Statistical analysis**

To describe the characteristics of patients we used counts and percentages for categorical variables, and medians with interquartile ranges for continuous variables. We compared the proportion of patients retained among the two groups: tracked patients, and those who resumed care before tracking started.

Kruskal–Wallis test was used for median CD4 lymphocyte counts, and Pearson Chi square test for proportions, or Fisher’s exact test for cell frequencies less than five. We used two-tailed tests, and an α-level of 0.05 for all our analyses. Since our sample size was small our comparisons were limited to bivariate analysis.

**Ethics**

The study was approved by the IDI Scientific Review Committee, and the Institutional Review Boards for School of Medicine, Makerere University College of Health Sciences, and the Uganda National Council for Science and Technology.

**Results**

From April 2011 to September 2013, 202 patients were followed up for 18 months after they returned to the IDC within 120 days of missing their visit. These included 85 tracked patients (42%) and 117 patients (58%) who resumed care spontaneously before tracking started. Therefore, the comparisons in this study were based on these two groups the tracked patients and those who resumed care spontaneously before tracking started (Figure 1).

The two groups were similar in gender, age, marital status, occupation, and distance of residence from the clinic, median duration on ART at last visit, median CD4 lymphocyte count at last visit and returning to care. They were different in WHO disease stage before missing a visit, proportion of patients retained, and causes of attrition at 18 months (Table 1).

Of all the study patients, 120 patients (59%) were women and 104 (52%) were married. One hundred sixty-four patients (81%) were residing within 20 km radius from the clinic and 160 (79%) were working. They had a median duration on ART of 30 months, a median CD4 lymphocyte count of 345 cells/mm$^3$ at their last visit before missing a visit, and 342 cell/mm$^3$ when they returned to the clinic (Table 1).

At 18 months of follow up, a total of 105 patients (52%) were still active in care, their median CD4 lymphocyte count was 437 cells/mm$^3$. Thirty-three of the traceable patients (39%), and 72 (61%) of those who resumed care before tracking started were still active in care ($p=0.000$) (Table 1).

There was a uniform rate of attrition over the 18 months of follow up. The most important cause of attrition among the traceable was self-transfer to another clinic (38 [73%] patients), whereas among those who resumed care before tracking was loss to follow up (LTFU) (32 [71%] patients). Mortality overall was low: only 6 patients (6%) were reported dead (Table 1).

**Discussion**

We found that only 39% of the traceable patients were retained in care after 18 months of follow up. Possible explanations for this low retention rate among the traceable patients are: first, it is likely that during tracking, home visitors advised patients to return to
the original clinic (IDC) for care. However, when these patients returned, the factors which led to their dropping out of care were not addressed.

Second, at the IDC, patients who miss their appointments are considered to be at risk of non-adherence. Consequently, they are reviewed by doctors on a monthly basis for a minimum of six months. It is possible that this is cumbersome for patients who are busy either because they are employed, or engaged in other income generating activities. Indeed, 79% of the patients in our study were working.

Third, the patients who self-transferred constituted 73% of the traceable patients. These patients were possibly in care at their preferred clinics. During tracking the home visitors should have encouraged them to stay at these clinics. Encouraging self-transferred patients to return to the original clinic, might lead to patients attending more than one clinic during the same period.

Of the patients who resumed care before tracking started, only 61% were in care at 18 months of follow up. The commonest cause of attrition among these patients was LTFU (71%). The IDC home visitors track all patients who miss their visits with a CD4 lymphocyte count <200 cells/mm³ and their outcomes are entered in the IDC database as they are more at risk

Figure 1. Retention at 18 months of patients who returned to care after a missed visit with or without tracking at a large HIV/AIDS Clinic, Uganda.
of dying if they interrupt their treatment. Therefore, any patient with an outcome of LTFU after 90 days might suggest that he/she has a CD4 lymphocyte count >200 cells/mm³. The important lesson from this finding is that all patients who miss their appointment, even for a few days, are at risk of attrition. Consequently, these patients should be targeted for adherence messages. Factors which hinder patients from keeping their appointment need to be identified, and dealt with. Unfortunately, our study never addressed this critical question.

Our study had a low incidence of mortality of only 6%. The possible explanations for this finding are: first, the patients had been on ART for a long time with a median duration of 30 months, mortality is reported to be higher in the first six months of starting treatment. Secondly, these patients had a high median CD4 lymphocyte count of 345 cells/mm³ at their last visit before missing a visit, mortality is higher with lower CD4 lymphocyte count <200 cells/mm³. Thirdly, the patients followed up in this study were out of the clinic for a short time, a maximum of 120 days. Mortality is expected to be higher if patients stop taking ARV drugs for a long time, or tracking is conducted late. Lastly, the patients were followed up for only 18 months, may be with longer follow up higher mortality could be observed.

Long-term retention of patients in care is a prerequisite for achieving optimal adherence and durable ART success. Therefore, we propose the following

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All, N (%)</th>
<th>Traceable a n (%)</th>
<th>RCBT n (%)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: Women</td>
<td>202 (100.0)</td>
<td>85 (42.1%)</td>
<td>117 (57.9%)</td>
<td>0.883</td>
</tr>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25–34</td>
<td>55 (27)</td>
<td>18 (21)</td>
<td>37 (32)</td>
<td>0.175</td>
</tr>
<tr>
<td>35–44</td>
<td>84 (42)</td>
<td>41 (48)</td>
<td>43 (36)</td>
<td></td>
</tr>
<tr>
<td>45+</td>
<td>63 (31)</td>
<td>26 (31)</td>
<td>37 (32)</td>
<td></td>
</tr>
<tr>
<td>Marital status: married</td>
<td>104 (52)</td>
<td>44 (52)</td>
<td>60 (51)</td>
<td>0.958</td>
</tr>
<tr>
<td>Occupation:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Business</td>
<td>105 (52)</td>
<td>51 (60)</td>
<td>54 (46)</td>
<td>0.237</td>
</tr>
<tr>
<td>Farming/agriculture</td>
<td>21 (10)</td>
<td>9 (11)</td>
<td>12 (10)</td>
<td></td>
</tr>
<tr>
<td>Formal employment</td>
<td>34 (17)</td>
<td>12 (14)</td>
<td>22 (19)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>42 (21)</td>
<td>13 (15)</td>
<td>29 (25)</td>
<td></td>
</tr>
<tr>
<td>Distance from the clinic within 20 km radius</td>
<td>164 (81)</td>
<td>72 (85)</td>
<td>92 (79)</td>
<td>0.702</td>
</tr>
<tr>
<td>Median duration on ART in months at last visit (IQR)</td>
<td>30 (10, 56)</td>
<td>29 (8, 54)</td>
<td>32 (11, 57)</td>
<td>0.426</td>
</tr>
<tr>
<td>Period between tracking and returning to clinic</td>
<td>Not applicable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30 days</td>
<td>9 (8)</td>
<td>9 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–60 days</td>
<td>28 (33)</td>
<td>28 (33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60–90 days</td>
<td>23 (28)</td>
<td>23 (27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>90–120 days</td>
<td>24 (30)</td>
<td>24 (29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR) CD4 count at last visit before missing a visit</td>
<td>345 (243, 516)</td>
<td>390 (242, 513)</td>
<td>338 (215, 525)</td>
<td>0.891</td>
</tr>
<tr>
<td>WHO stage III or IV at last visit before missing a visit</td>
<td>146 (72)</td>
<td>55 (65)</td>
<td>91 (78)</td>
<td>0.034</td>
</tr>
<tr>
<td>Median (IQR) CD4 count when patient returned to clinic</td>
<td>342 (215, 495)</td>
<td>385 (212, 513)</td>
<td>332 (236, 502)</td>
<td>0.287</td>
</tr>
<tr>
<td>Patients still active in care at 18 months</td>
<td>105 (52)</td>
<td>33 (39)</td>
<td>72 (61)</td>
<td>0.000</td>
</tr>
<tr>
<td>Median (IQR) CD4 count at 18 months</td>
<td>437 (293, 582)</td>
<td>501 (381, 646)</td>
<td>396 (282, 562)</td>
<td>0.382</td>
</tr>
<tr>
<td>Causes of attrition at 18 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-transferred</td>
<td>49 (51)</td>
<td>38 (73)</td>
<td>11 (25)</td>
<td>0.001 b</td>
</tr>
<tr>
<td>Lost (never returned to clinic for &gt;90 days)</td>
<td>42 (43)</td>
<td>10 (19)</td>
<td>32 (71)</td>
<td></td>
</tr>
<tr>
<td>Dead</td>
<td>6 (6)</td>
<td>4 (8)</td>
<td>2 (4)</td>
<td></td>
</tr>
</tbody>
</table>

IQR, interquartile range; RCBT: resumed care before tracking.

aTraceable: self-transferred and planning to come back.
bFisher’s exact test.
measures to increase the efficiency of tracking, as well as retention rate at ART clinics. (1) Treatment centres should provide a telephone service patients can contact when they cannot attend the clinic, and that can reschedule appointments. Contact addresses of patients should be regularly updated.10,15,16 (2) Patients who return to the clinic after a missed appointment should be interviewed to identify possible reasons for missing the appointment. Difficulties which patients may have in keeping appointments must be addressed. (3) The number of pills dispensed to patients should be documented in the medical records. This will allow more efficient tracking, targeting patients who must be without pills, or are at risk of running out of pills. (4) Patients who missed their appointment but plan to return should provide their intended dates of coming back. (5) Patients who self-transferred should be encouraged to continue care at their preferred clinics. (6) Treatment centres should provide patients with information about retention and care which includes sensitisation on the formal way of transferring their care to other centres, the need to inform the current care giver if they obtain care from another centre and advocate for further decentralisation of ART services. ART clinics should adapt their services for busy patients who are clinically stable. Measures to consider are offering three- or six-monthly appointments,17 distribute drugs at the patients’ home by a community worker, or having clinics open in the evenings and weekends.

In conclusion, our study shows that tracked patients who resumed care following a missed appointment are at high risk of attrition. Most attrition was due to transfer out, and was uniform during the 18 months of follow up. In order to increase retention, ART clinics may need to adopt a chronic care model which takes into consideration patients’ changing needs, and their preference for self-management. Implementing such a chronic care model has the advantage of requiring less health workers.

Acknowledgements

The authors would like to thank all the patients and staff for all their contributions toward the conduct of the study. We also like to thank the Belgian Technical Cooperation (BTC), Gilead, San Francisco and Infectious Diseases Institute for financial support. Special thanks to Agnes Kiragga, Richard Orama, Barbara Castelnuovo and Racheal Musomba for their contribution in the streamlining tracking of patients at the IDC.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

References


Downloaded from std.sagepub.com at INST OF TROPICAL MED LIBRARY on December 15, 2014
initiating triple drug therapy. *JAMA* 2001; 286(20): 2568–2577.


