

# Evaluating Outcomes of Patients Lost to Follow-up in a Large Comprehensive Care Treatment Program in Western Kenya

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**Background:** Academic Model Providing Access To Healthcare (AMPATH) program provides comprehensive HIV care and treatment services. Approximately, 30% of patients have become lost to follow-up (LTFU). We sought to actively trace and identify outcomes for a sample of these patients.

**Methods:** LTFU was defined as missing a scheduled visit by  $\geq 3$  months. A randomly selected sample of 17% of patients identified as LTFU between January 2009 and June 2011 was generated, with sample stratification on age, antiretroviral therapy (ART) status at last visit, and facility. Chart reviews were conducted followed by active tracing. Tracing was completed by trained HIV-positive outreach workers July 2011 to February 2012. Outcomes were compared between adults and children and by ART status.

**Results:** Of 14,811 LTFU patients, 2540 were randomly selected for tracing (2179 adults, 1071 on ART). The chart reviews indicated that 326 (12.8%) patients were not actually LTFU. Outcomes for 71% of sampled patients were determined including 85% of those physically traced. Of those with known outcomes, 21% had died, whereas 29% had disengaged from care for various reasons. The remaining patients had moved away ( $n = 458$ , 25%) or were still receiving HIV care ( $n = 443$  total, 25%).

**Conclusions:** Our findings demonstrate the feasibility of a large-scale sampling-based approach. A significant proportion of patients were found not to be LTFU, and further, high numbers of patients who were LTFU could not be located. Over a quarter of patients disengaged from care for various reasons including access challenges and familial influences.

**Key Words:** lost to follow-up, sampling, outreach, tracing, HIV/AIDS

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## INTRODUCTION

Improved access to HIV care and especially antiretroviral therapy (ART) globally has resulted in decreases in HIV-related morbidity and mortality.<sup>1–5</sup> Among people living with HIV/AIDS, retention in HIV care programs is critical for achieving timely treatment initiation and viral suppression. Continuous engagement in care is also programmatically critical for positively impacting HIV incidence.<sup>1,5</sup> Disruption in HIV care through missed visits/appointments can undermine clinical outcomes<sup>6</sup>; retention in HIV care programs remains a major challenge across settings.<sup>7–10</sup> A 2010 review of 39 sub-Saharan ART cohorts reported that approximately 25% (11%–32%) of patients were no longer in care after 2 years of treatment with ART. After adjusting for variable follow-up among the various cohorts in sensitivity analysis, median attrition at 2 years was 30% (27%–33%). Attrition was mostly due to losses to follow-up followed by death.<sup>9</sup>

The dynamic complexities individuals face during the course of their HIV care (eg, logistical challenges)<sup>11–25</sup> can impact on their ability to return to the clinic for scheduled follow-up visits. This, in turn, places individuals at high risk for disease progression, drug resistance, and death.<sup>11,26–30</sup> At the same time, program planners remain uncertain about how and where to direct outreach and return-to-care efforts.<sup>6,11,31,32</sup> Large numbers of losses to follow-up can indicate poorly designed programs that do not meet patient needs as well as ineffective or inefficient use of program resources. Patient tracing through outreach activities is commonly used to track individuals who miss scheduled visits to determine their

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status and encourage their return to care.<sup>32,33</sup> This occurs through direct contact with the patient but can also include discussions with neighbors, family members, and friends when the patient cannot be found or is known to have died. True outcomes of adults and children lost to follow-up (LTFU) are difficult to assess and HIV care clinics continue to face operational challenges when it comes to finding patients who miss visits. Studies that identify outcomes of patients who are traced are an important way of improving quality of care.<sup>34</sup> Despite increasing numbers of individuals in HIV care and on ART,<sup>35</sup> health worker shortages, organizational challenges, and high costs continue to limit the ability of HIV programs to trace all patients who are missing or LTFU. Attempting to trace all patients can result in biased estimates, particularly if a large proportion of those lost could not actually be located. However, tracing only a sample of patients may be considered as a “scalable alternative,”<sup>36</sup> as analyses of data obtained on patients who are actually located can allow for the adjustment of mortality and LTFU estimates. We have previously demonstrated the effectiveness of sampling-based approaches for improving estimates of patient retention and survival.<sup>36–39</sup>

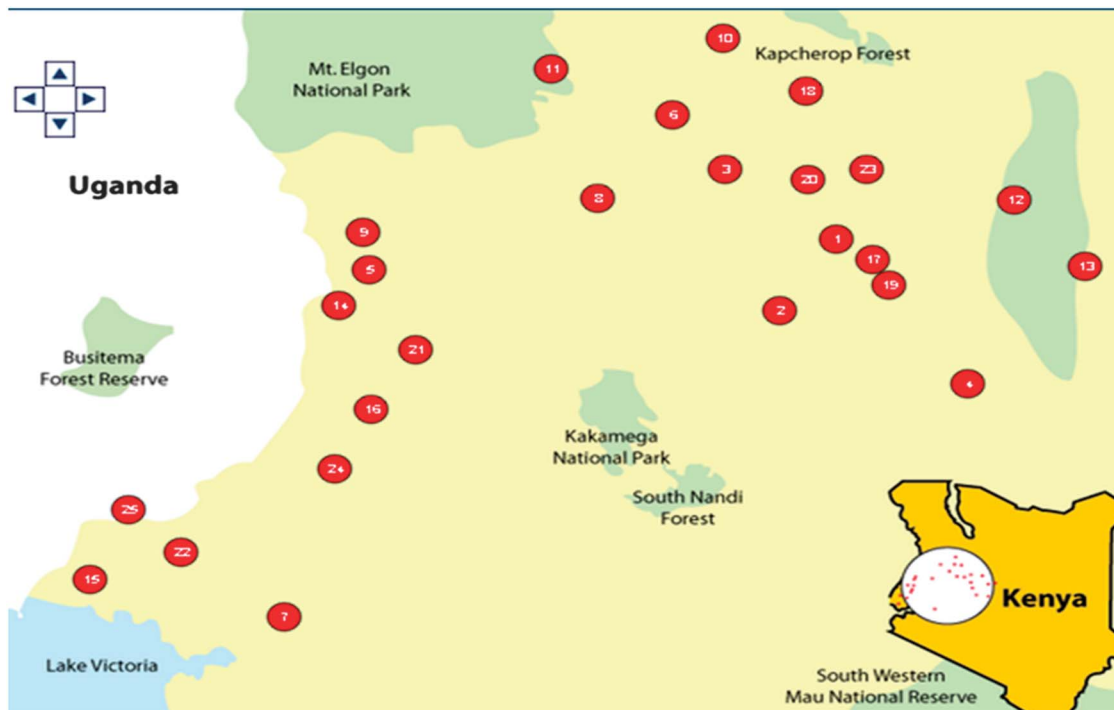
The Academic Model Providing Access to Healthcare (AMPATH) program was initiated in 2001 in response to the HIV epidemic in western Kenya. It has enrolled over 130,000 HIV-infected patients and 21,000 HIV-exposed infants in >65 Ministry of Health facilities throughout western Kenya (Fig. 1). Approximately, 30% of these patients have become LTFU since 2001; however, tracing all patients known to be LTFU in our setting is difficult for the reasons highlighted above.<sup>36</sup> Therefore, the objective of this study was to trace only a sample of those LTFU to document their reasons for becoming LTFU and inform program improvement and patient monitoring.

## METHODS

### Academic Model Providing Access to Healthcare

As of 2012, an estimated 5.6% of Kenyans aged 15–64 years were estimated to be HIV positive,<sup>40</sup> although prevalence varies geographically, with the highest prevalence (15%) demonstrated in the western region of Nyanza.<sup>41</sup> ART has been provided through the public sector since 2006 and as of 2012, it is estimated that 61% of treatment-eligible adults were receiving ART.<sup>42,43</sup>

The AMPATH Consortium, based in Eldoret, Kenya (about 350 km northwest of Nairobi) was initiated in 2001 as a joint partnership between Moi University School of Medicine, Moi Teaching and Referral Hospital (MTRH),<sup>44,45</sup> and a consortium of North American universities led by Indiana University (IU) School of Medicine. With financial support from United States Agency for International Development (USAID), the USAID-AMPATH Partnership was established in 2004. The AMPATH Consortium provides technical support, mentorship, and training to Kenyan medical faculty and staff with the aim of developing health care services in Kenya. AMPATH has enrolled over 130,000 HIV-infected adults and children plus 21,000 HIV-exposed infants in >65 Ministry of Health facilities around western Kenya. Currently, nearly 80,000 patients are actively followed, 83% of whom are on combination ART; 21% are aged ≤14 years. All HIV and tuberculosis-related care and treatment are free at the point of service for patients. Patients are managed according to National Kenyan protocols, which are consistent with World Health Organization (WHO) guidelines. Clinic visits occur monthly for all patients on



**FIGURE 1.** Study sites in western Kenya.

ART unless alternative arrangements have been made with their health care provider. Patients who are not yet eligible for treatment are seen monthly or bimonthly depending on their immunologic status and other factors in their health profile. Standard paper data collection forms are used at enrollment to the program and at each subsequent visit. Data from these forms are entered into the AMPATH electronic Medical Record System (AMRS)<sup>46,47</sup> by data entry technicians.

## Outreach Program

AMPATH has a robust mechanism for following up patients who miss clinic visits. Trained and remunerated HIV-positive peers with records of perfect clinic and/or treatment adherence contact patients by phone or through home visits if they miss a scheduled clinic visit.<sup>48</sup> Active outreach of patients who miss scheduled visits started in January 2005 at 2 of the AMPATH Clinics: Moi Teaching and Referral Hospital (MTRH), an urban referral hospital located in Eldoret and Mosoriot, a rural health center, which serves a catchment area of approximately 6000 located about 30 km from Eldoret. The program now covers all AMPATH clinics. AMRS produces a daily list of patients scheduled for visits and patients who miss theirs are listed for outreach. Adult patients on ART for less than 3 months are given priority with outreach efforts beginning within 24 hours of a missed visit. Ideally, patients will be found within 7 days. Outreach for patients who have been on ART for more than 3 months begins within 7 days after a missed visit. Tracing for pre-ART individuals is not initiated until 28 days after a missed visit. At the time of this study, the outreach program maintained a standalone MS Access database that contained data pertaining to every outreach encounter including vital status of located patients and date of death for patients found to be deceased. This database has since become part of the AMRS. Mortality ascertainment is determined through a program-wide Standard Operating Procedure and Form for Death Reporting in which all deaths are recorded and reported to the central data system for documentation in the AMRS, including deaths identified in the course of patient tracing. Note that all patients are asked to provide telephone and locator information at every visit for the purposes of tracing. This includes home visits in the event a patient misses a scheduled visit. They provide verbal consent in the context of the care program.

## Definition of LTFU

LTFU was defined as absence from clinic, without known death or transfer to another facility, for at least 3 months since a last scheduled visit.

## Sample

All patients (including adults and children as well as those on and off ART) enrolled in AMPATH, who had made a visit between January 2009 and July 2011, were identified as the population of interest. From this cohort, we identified patients who were LTFU. We stratified the sample on clinic

site, ART status at last clinic visit, and age (categorized as adults and children) to ensure adequate representation within each of these strata. We selected 17% of LTFU patients within each of these categories based on an assessment of practical, theoretical, and statistical considerations. Previous work suggests that a 10%–20% sample provides optimal precision gained per patient sampled.<sup>36</sup> Within this range, we took the largest sample we felt was feasible to trace with the given resources.

## Measures

First, chart reviews were undertaken, while the second step involved active tracing of patients who after chart review, were still deemed LTFU. Standardized data extraction forms were used for data collection. Outreach workers fill out a locator card for all patients who enroll into the clinical care program, which includes the patients contact information as well as a map to get to their residence including landmarks. This information is used to find the patient in the event of a missed appointment. If sampled patients were untraceable, information was obtained from an informant familiar with the patient (eg, family member, neighbor). Outreach workers will attempt to locate the patient at least 3 times. Reasons why patients stopped going to any clinic for HIV care are captured and divided into 5 main categories: Access to Care (6 items), Clinic Quality (5 items), Work and Family (3 items) Medical (6 items), and Alternative Treatment and Advice (4 items). Importantly, patients could provide more than 1 reason for disengaging. Tracing of patients was initiated in July 2011 and was completed in February 2012. This study was reviewed and approved by institutional review bodies of all participating sites and universities, including Moi University College of Health Sciences, Moi Teaching and Referral Hospital, Indiana University, and the University of California, San Francisco.

## Analysis

Data analysis was performed using SAS version 9.3. Categorical variables were summarized as frequencies and the corresponding percentages. Association between categorical variables was assessed using Pearson  $\chi^2$  test and the associated *P* values were reported. Fisher exact test was used when the expected cell frequencies in the constructed  $\chi^2$  tables were less than 5. Results were considered statistically significant when *P* < 0.05. The data for a total of 2540 participants, adults and children, were included for analysis. Comparisons were explored for adults versus children as well as between individuals on ART and individuals not on ART.

## RESULTS

### Summary of Findings

Of the 14,811 patients identified as LTFU during the study period, 2540 were randomly selected for tracing including 2179 (85.8%) adults and 361 (14.2%) children. A total of *n* = 1071 (42%) were on ART. The median time on ART was 432 days (interquartile range, 124–827). Figure 2

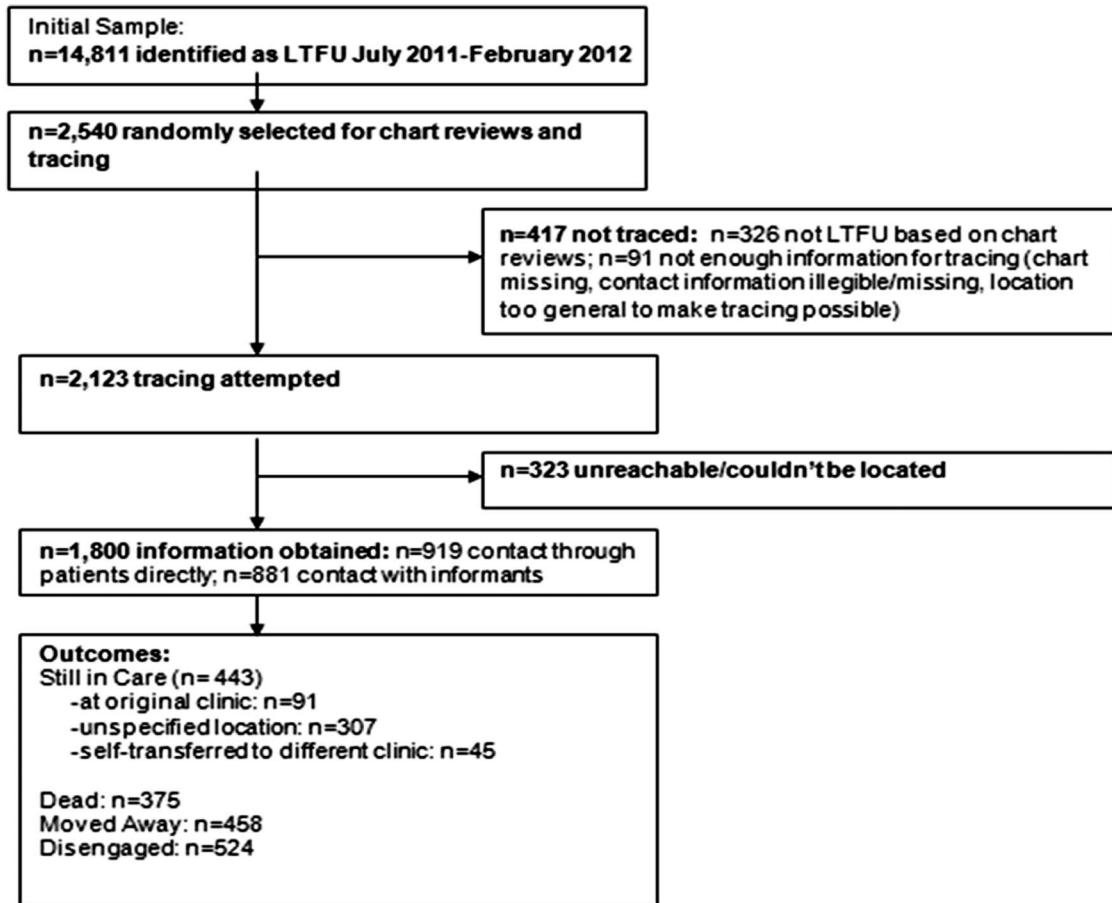


FIGURE 2. Flow of patient outcomes through the study.

demonstrates the flow of patients and their outcomes through this study. Over 70% of all patients in this study (n = 1800) were successfully traced and outcomes could be determined for 85% of those who were physically traced. Table 1 presents the summary of patient tracing outcomes. Of those successfully traced, 881/1800 (49%) had their whereabouts obtained through an informant, whereas 919/1800 (51%) patients were communicated with directly. Significantly, more children (190/361, 52.6%) were communicated to directly (through a guardian and/or parent) compared with adults (729/2179, 33.5%,  $P < 0.001$ ).

### Outcomes of Chart Review

The chart reviews demonstrated that 326/2540 (12.8%) patients were not actually LTFU: n = 50/326 (15.3%), had died n = 16/326 (4.9%) were HIV negative, n = 47/326 (14.4%) had a recent visit at their original AMPATH clinic, n = 45/326 (14.0%) were in care at another AMPATH clinic, and n = 168/326 (51.5%) had transferred out of AMPATH. Among the n = 326 patients found not to be LTFU, significantly more children (28.1% of all children not LTFU) were found to be HIV negative compared with adults (0% of all adults not LTFU). A higher proportion of adults had

TABLE 1. Summary of Tracing Results (N = 2540)

|                               | Patient Type, n (%) |            |            | P       | ART Status, n (%) |            |         |
|-------------------------------|---------------------|------------|------------|---------|-------------------|------------|---------|
|                               | All                 | Adults     | Children   |         | Off               | On         | P       |
| Successfully traced           | 1800 (70.9)         |            |            | <0.0001 |                   |            | <0.0001 |
| Communicated with patient     | 919 (51.1)          | 729 (33.5) | 190 (52.6) |         | 563 (38)          | 356 (33)   |         |
| Communicated with informant   | 881 (48.9)          | 811 (37.2) | 70 (19.4)  |         | 496 (34)          | 385 (36)   |         |
| Unreachable                   | 740 (29.1)          |            |            |         |                   |            |         |
| Attempted but could not trace | 323 (43.6)          | 287 (13.2) | 36 (10)    |         | 213 (15)          | 110 (10)   |         |
| Not attempted (Table 2)       | 417 (56.4)          | 352 (16.2) | 65 (18)    |         | 195 (13)          | 220 (21)   |         |
|                               | 2540 (100)          | 2179 (100) | 361 (100)  |         | 1467 (100)        | 1071 (100) |         |

a recent visit at their original AMPATH clinic (15.6% of all adults not LTFU vs. 8.8% of all children not LTFU) or had transferred out (52.3% vs. 38.6%). Significantly, more patients on ART had died compared with pre-ART patients (19% of all ART patients not LTFU vs. 10% of all non-ART patients not LTFU).

### Tracing Process Outcomes

A total of 1800/2540 (70.8%) patients were successfully traced: 881/1800 (49%) had their whereabouts obtained through an informant, whereas 919/1800 (51.0%) patients were communicated with directly. Of all patients, a total of 740/2540 (29.1%) patients were not traced. Tracing was attempted but not successful for  $n = 323/740$  (43.6%) patients. Tracing was not attempted for 417/740 (56.4%) patients: the chart was missing ( $n = 2$ , 0.5%), contact information was illegible ( $n = 4$ , 1.0%), missing ( $n = 30$ , 7.2%), or too general ( $n = 36$ , 8.6%) to make tracing possible (Table 2). There was a significant association between ART status and tracing results ( $P < 0.001$ ) with tracing not attempted in a higher proportion of ART patients compared with pre-ART patients (21% vs. 13%). A higher proportion of pre-ART patients had missing contact information needed to make tracing possible (13% vs. 2%), whereas a higher proportion of patients on ART (190/220, 86%) were found not actually to have been LTFU compared with pre-ART patients (135/195, 69%).

### Outcomes of Tracing

Outcomes of patients whose status was successfully determined through contact with patients themselves or through informants are presented in Table 3 ( $n = 1800$ ). A total of 375/1800 (20.8%) patients had died. A higher proportion of adults (23.6% vs. 4.6%) and patients on ART (26.0% vs. 17.0%) had died compared with children and pre-ART patients, respectively ( $P < 0.001$ ). Among those found alive, 458/1425 (32.1%) had moved away, whereas 443/1425

(31.1%) reported that they had received care in the last 3 months. Of these,  $n = 91/443$  (20.5%) were in care at their original clinic,  $n = 45/443$  (10.2%) had self-transferred to another clinic, and  $n = 307/443$  (69.3%) were in care at an unspecified location. The remaining patients had disengaged from care ( $n = 524/1800$ , 29.1% of those successfully traced). A higher proportion of children (119/260, 45.8%) and ART patients (347/1059, 33%) had disengaged from care compared with adults (405/1540, 26.3%) and pre-ART patients (177/741, 24%) ( $P < 0.001$ ).

### Reasons for Disengaging From Care

Table 4 outlines the reasons for disengaging from care. Access to Care (reported by  $n = 219$  patients), Clinic Factors ( $n = 132$  patients), Work and Family ( $n = 247$  patients), Medical ( $n = 209$  patients), and those related to Alternative Treatment and Advice ( $n = 37$  patients). The most commonly reported reasons why patients disengaged from care were as follows: felt well so did not need care ( $n = 140$  patients), transport was too difficult or expensive ( $n = 84$  patients), and work or need for money interfered with picking up medicine ( $n = 64$  patients). Differences between adults and children and between ART and pre-ART patients are presented in Table 4. Among those who reported Access to Care challenges, a higher proportion of children (57.5%) and individuals on ART (44.9%) reported that transport was too difficult or expensive compared with adults (34.1%) and individuals not on ART (35.3%), respectively. For those reporting Clinic Factors, a higher proportion of children and individuals on ART reported that they were afraid of scolding compared with adults (73.3% vs. 27.4%) and individuals not on ART (43.4% vs. 26.7%). A higher proportion of adults reported staff not being nice as a reason for disengaging from care compared with children (10.3% vs. 0%). A higher proportion of individuals not on ART reported that they felt so well they did not need care compared with ART patients (85.7% vs. 35.6%). Of those citing wanting to access Alternative Treatment and Advice, a higher proportion of adults

**TABLE 2.** Reasons for Not Tracing (N = 417)

|   | Patient Type, n (%) |            |           |        | ART Status, n (%) |            |        |
|---|---------------------|------------|-----------|--------|-------------------|------------|--------|
|   | All                 | Adults     | Children  | P      | Off               | On         | P      |
| Chart missing                                       | 2 (<1)              | 2 (0.6)    | 0         | 0.397  | 1 (0.5)           | 1 (0.5)    | 0.0001 |
| Contact information illegible                       | 4 (<1)              | 3 (0.9)    | 1 (1.5)   |        | 3 (1.5)           | 1 (0.5)    |        |
| Contact information missing                         | 30 (7.2)            | 27 (7.7)   | 3 (4.6)   |        | 25 (13)           | 5 (2)      |        |
| Location listed to general to make tracing possible | 36 (8.6)            | 33 (9.4)   | 3 (4.6)   |        | 20 (10)           | 16 (7)     |        |
| Other   | 19 (4.6)            | 18 (5.1)   | 1 (1.5)   |        | 11 (6)*           | 7 (3)      |        |
| Not lost to follow-up                               | 326 (78.2)          | 269 (76.4) | 57 (87.7) |        | 135 (69.0)        | 190 (86.0) |        |
| Dead  | 50 (15.3)           | 42 (15.6)  | 8 (14.0)  | 0.0001 | 14 (10)           | 36 (19)    | <0.001 |
| HIV negative  | 16 (4.9)            | 0          | 16 (28.1) |        | 16 (12)           | 0 (0)      |        |
| Has a recent visit at original AMPATH clinic        | 47 (14.4)           | 42 (15.6)  | 5 (8.8)   |        | 18 (13)           | 28 (15)    |        |
| Transferred to another AMPATH clinic                | 45 (14)             | 39 (14.5)  | 6 (10.5)  |        | 19 (14)           | 26 (14)    |        |
| Transferred out of AMPATH                           | 168 (51.5)          | 146 (52.3) | 22 (38.6) |        | 68 (50)           | 100 (53)   |        |
| Total   | 417 (100)           | 352 (100)  | 65 (100)  |        | 195 (100)         | 220 (100)  |        |

\*n = 1 missing.

**TABLE 3.** Outcomes of Patients Who Were Successfully Traced (N = 1800)

|                                     | Patient Type, n (%) |            |            |        | ART Status, n (%) |            |        |
|-------------------------------------|---------------------|------------|------------|--------|-------------------|------------|--------|
|                                     | All                 | Adults     | Children   | P      | No                | Yes        | P      |
| Still in care (n = 443) (24.6%)     |                     |            |            |        |                   |            |        |
| Getting care in the original clinic | 91 (20.5)           | 79 (5.1)   | 12 (4.6)   | <0.001 | 46 (4.0)          | 45 (6.0)   | <0.001 |
| Other/not specified                 | 307 (69.3)          | 250 (16.2) | 57 (21.9)  |        | 174 (16.0)        | 133 (18.0) |        |
| Self-transferred (still in care)    | 45 (10.2)           | 40 (2.6)   | 5 (1.9)    |        | 24 (2)            | 21 (3)     |        |
| Other (n = 1357) (75.4%)            |                     |            |            |        |                   |            |        |
| Moved away                          | 458 (25.4)          | 403 (26.2) | 55 (21.2)  |        | 286 (27)          | 172 (23)   |        |
| Dead                                | 375 (20.8)          | 363 (23.6) | 12 (4.6)   |        | 182 (17)          | 193 (26)   |        |
| Disengaged (Table 4)                | 524 (29.1)          | 405 (26.3) | 119 (45.8) |        | 347 (33)          | 177 (24)   |        |
| Total                               | 1800 (100)          | 1540 (100) | 260 (100)  |        | 1059 (100)        | 741 (100)  |        |

(48.4%) and ART patients (52.9%) reported that they went to someone trying to cure HIV by prayer/religious rituals compared with children (0%) and individuals not on ART (30%), respectively.

**DISCUSSION**

In this study, we successfully identified outcomes for 71% of sampled patients initially identified as being LTFU and 85% of those physically traced. These findings suggest

that a large-scale sampling-based outreach program can be both feasible and effective in locating patients suspected of being LTFU and determining their status. Of those with known outcomes, 21% had died, whereas another 25% of patients were not actually LTFU and still were receiving care within AMPATH or elsewhere. Related to this is the high proportion of individuals who could not be traced suggesting accurate and up-to-date information on patient status is needed at each follow-up. Finally, over a quarter of patients who were found had chosen to disengage from care for

**TABLE 4.** Reasons for Disengaging From Care (N = 524 Patients Provided Reasons)\*

| Category  | Total      | Patient Type, n (%) |           | ART, n (%) |           |
|---|------------|---------------------|-----------|------------|-----------|
|   |            | Adult               | Children  | Off        | On        |
| Access to care  | n = 219    | n = 179             | n = 40    | n = 150    | n = 69    |
| Transport too difficult or expensive  | 84 (38.4)  | 61 (34.1)           | 23 (57.5) | 53 (35.3)  | 31 (44.9) |
| Transport too difficult or expensive or no money to access care               | 54 (24.7)  | 46 (25.7)           | 8 (20.0)  | 42 (28.0)  | 12 (17.4) |
| Spent too much time in clinic   | 27 (12.3)  | 26 (14.5)           | 1 (2.5)   | 19 (12.7)  | 8 (11.6)  |
| Clinic factor   | n = 132    | n = 117             | n = 15    | n = 86     | n = 46    |
| Afraid of scolding  | 43 (32.6)  | 32 (27.4)           | 11 (73.3) | 23 (26.7)  | 20 (43.4) |
| Attending clinic risked disclosure to community                               | 37 (28.0)  | 35 (29.9)           | 2 (13.3)  | 28 (32.6)  | 9 (19.6)  |
| Staff was not nice  | 12 (9.1)   | 12 (10.3)           | 0 (0)     | 7 (8.1)    | 5 (10.9)  |
| Work and family   | n = 247    | n = 206             | n = 41    | n = 161    | n = 86    |
| Work or need for money interfered with picking up medicine                    | 64 (25.9)  | 56 (27.2)           | 8 (19.5)  | 41 (25.5)  | 23 (26.7) |
| Care for family   | 42 (17.0)  | 31 (15.1)           | 11 (26.8) | 26 (16.2)  | 16 (18.6) |
| Family conflict   | 31 (12.6)  | 21 (10.2)           | 10 (24.4) | 24 (14.9)  | 7 (8.1)   |
| Attending clinic risked disclosure to family that I had HIV                   | 31 (12.6)  | 27 (13.1)           | 4 (9.8)   | 19 (11.8)  | 12 (14.0) |
| Work or need for money interfered with picking up medicine or care for family | 18 (7.3)   | 15 (7.3)            | 3 (7.3)   | 9 (5.6)    | 9 (10.5)  |
| Care for family and family conflict   | 14 (5.7)   | 13 (6.3)            | 1 (2.4)   | 9 (5.6)    | 5 (5.8)   |
| Medical   | n = 206    | n = 159             | n = 47    | n = 133    | n = 73    |
| Felt well so did not need care  | 140 (68.0) | 103 (64.8)          | 37 (78.7) | 114 (85.7) | 26 (35.6) |
| Alternative treatment and advice  | n = 37     | n = 31              | n = 6     | n = 20     | n = 17    |
| Went to someone who tried/is trying to cure me by prayer/religious rituals    | 15 (40.5)  | 15 (48.4)           | 0 (0)     | 6 (30.0)   | 9 (52.9)  |
| Family person or important person asked me to stop from going to clinic       | 611 (29.7) | 8 (25.8)            | 3 (50.0)  | 6 (30.0)   | 5 (29.4)  |

\*Percentages calculated separately for each category. Only most common reasons for each category are presented.

various reasons. Compared with adults, a higher proportion of children were found not to be LTFU, and of those successfully traced, a higher proportion were ascertained as being still in care at an AMPATH clinic.

Our findings reinforce the challenges associated with obtaining and maintaining up-to-date information on the locations and status of patients who miss their scheduled visits. A recent Malawian study noted that poor documentation was among the top reasons for explaining why patients may become LTFU.<sup>49</sup> The quality of collected data varies widely across large longitudinal cohorts<sup>50,51</sup> with data management being particularly challenging in many resource-poor settings.<sup>50,52–55</sup> This can be due to poor infrastructure, a shortage of trained personnel, an unbalanced provider-patient ratio,<sup>54,56</sup> and a lack of investment by implementers and funders in electronic health records systems. It is worth noting that HIV programs with electronic monitoring capabilities,<sup>50,51</sup> such as AMPATH's AMRS, have demonstrated better-quality data. Regardless, the findings of this study indicate that 25% of sampled patients were not even LTFU (ie, were still in care). Although there were patients who truly did miss their visits, poor documentation led some patients to be incorrectly labeled as LTFU. A significant proportion of patients in this study originally considered LTFU were later confirmed to have transferred out, either to another AMPATH clinic or out of the program entirely (Table 3). Similar findings have been found elsewhere.<sup>56</sup> Therefore, missing patients may have transferred to another clinic and thus are only LTFU from the perspective of their original clinic.<sup>50</sup> Similarly, patients may be misclassified as LTFU<sup>56</sup> when patient files were lost or the visit itself was not recorded. Findings from the chart review suggest that 47 patients had actually had a recent visit (Table 2) and another 25% of patients found through tracking reported that were still in care (Table 3). A higher proportion of pre-ART patients had missing contact information making tracing difficult compared with ART patients. This may be partially explained by the frequency of visits with the latter group being expected to come to the clinic more frequently (and thus have more opportunities to collect information) than those not yet on ART. Identifying where (eg, which clinics) and when (eg, data entry, filing) errors occur is needed. An accurate record of the date of the next expected visit is needed to calculate the discrepancy between the expected return date and an actual return date. This can help program planners and clinicians to identify situations where patients may require additional support and management.

Patients who miss scheduled visits need to be followed up to ascertain their status (eg, alive, in care, died, etc.) and to adjust program LTFU and mortality estimates.<sup>57,58</sup> In this study, death was a primary outcome of patients LTFU suggesting that death reporting clearly needs improvement. In Kenya, although mortality is reported using routine health facility reports, these do not include deaths that occur at home and as a result, mortality estimates are likely underestimated in this context.<sup>59</sup> A 2013 review of ART programs in low- and middle-income settings reported that programs that incorporated physical tracing had lower estimates of LTFU and higher estimates of mortality.<sup>33</sup> Since risk factors for losses to

follow-up and mortality can be similar (eg, lower CD4 count at enrollment), estimates that do not account for patients considered lost but who have actually died can severely underestimate the true extent of mortality and conversely overestimate the positive impact of a care and treatment program.<sup>36</sup> As successful outreach can lead to increased "re-engagement with care,"<sup>33</sup> accurate information on patient locations is needed to ensure patients can actually be found. In this study, 85% of the individuals confirmed to be LTFU (eg, based on chart reviews) could be physically traced. Importantly, one of the strengths of the AMPATH outreach program is the level of detail captured on patient physical locations at the time of enrollment. Phone numbers are also verified at each visit. Importantly, a working phone number is one of the strongest predictors of successfully finding patients.<sup>34,60</sup> Since 2009, AMPATH has captured geographic coordinates using Global Position System during home-based testing and counseling.<sup>61</sup> This can further assist outreach workers in locating patients in the future. Home visits, however, can lead to involuntary disclosure of one's HIV status<sup>62</sup> emphasizing the need to consider not only who physically traces patients but also how outreach efforts are implemented in general.

Over a quarter of sampled patients disengaged from care on their own. Challenges accessing care were among the most frequently reported reasons why patients missed their visits. This may be particularly challenging for parents/guardians who need to travel with their child/children, adding to transport costs. Financial constraints<sup>12–14</sup> and transport-related costs<sup>11,13,15–18</sup> have been shown to be important for losses to follow-up, particularly when individuals have to choose between using their limited income on transport, or food to feed themselves and their families.<sup>19</sup> Negotiating transport continues to present challenges and while arranging for transport (on behalf of the patient) and/or reimbursing patients for travel costs<sup>20,54</sup> may not be a feasible long-term solution, other strategies need to be investigated. This can include less frequent visits for patients deemed stable<sup>20</sup> or arranging for 1 individual to pick up medication for a larger group. Regardless, ethical considerations are needed with respect to the provision of incentives in settings with widespread poverty. Stigma and fear of disclosure<sup>11,20–22</sup> was reported as a reason for disengagement with fear of scolding and mistreatment by health care staff and family influences being particularly important. Poor patient-provider relationships<sup>11,14,49</sup> are an important reason why individuals choose to disengage from care. Frustrations with the health care they receive and the use of exposing language<sup>20,49</sup> that essentially "outs" their positive HIV status to others in the clinic have been previously the reasons for becoming LTFU. Family influences can also discourage patients from staying in care<sup>12–14,16,21,22,49</sup>; here, almost 30% of interviewed patients reporting issues related to Alternative Treatment and Advice specifically indicated that "family or close friends asked them to stop going to the clinic." Importantly, health care delivery models that acknowledge patient fears are critical as these can undermine relationships, which are essential for survival.<sup>23,24</sup>

The most commonly reported reason why patients in this study disengaged from care were that they felt well. Not surprisingly, a higher proportion of pre-ART patients reported

that they felt well enough to not require care. Previous studies have demonstrated that ART patients may become lost for similar reasons, particularly if they have been on ART for longer periods of time. Being on ART can provide individuals with a renewed sense of life<sup>12,25</sup> and feeling better and experiencing an improvement in health can lead to an increased risk of stopping ART and disengaging from care.<sup>11,20,49</sup> This can lead to a resurgence in viral load, and increase the risk of opportunistic infections and/or death.<sup>11,26–</sup>

<sup>30</sup> Indeed, the health-seeking behaviors of many African populations, including Kenyans, suggest that individuals may only seek care when symptomatic and/or when health becomes a top priority over other life challenges.<sup>63–65</sup> In addition to continued patient education on treatment literacy (eg, understanding the need to take medication as prescribed),<sup>66,67</sup> creative strategies involving community-based approaches can also work to engage asymptomatic HIV-positive individuals with care.

This study has numerous strengths including the large study sample and the high proportion of patients who could be physically traced pointing to the feasibility of large-scale outreach programs. Furthermore, by including both adults and children as well individuals on and off ART, we were able to generate a snapshot of outcomes in our setting. The broad inclusion criteria also increase the generalizability of our findings to other settings and programs. However, there were several limitations in this study. The reasons why patients disengaged may be subject to social desirability responding, particularly if patients fear disclosing their frustrations around the care they receive. Patients who are LTFU are, by definition, a hard group to follow-up. Patients successfully found in this study may be different from those who were not traceable, and therefore, the reasons why patients disengage from care may not be generalizable to the latter group. However, by including both children and adults on and off treatment in this study, we were able to generate a population-wide snapshot identifying outcomes of patients LTFU in our setting. Individuals not successfully found through outreach efforts may have died, therefore, to correct for mortality and LTFU estimates, there is a clear need to distinguish patients who have died from individuals who have become LTFU for other reasons. Other reasons for why patients may disengage from care on their own accord may not be captured in this study. For example, reasons specific to ART such as experiencing side effects are not captured nor explored in this study.

In this study, we were able to successfully identify outcomes for a high proportion of individuals reported to be LTFU. Importantly, we found that a proportion of patients initially identified as LTFU were not actually LTFU indicating the importance of maintaining up-to-date information on patient status as well as the need for accurate details on visit history and patient locations to assist with timely tracing. Future research should work to identify where and when errors occur and how to improve coordination between clinics when there are transfers involved. Related to this is the need to capture details on deaths as they occur, at the national level, to correct mortality and LTFU estimates. The findings of this study have implications for the development and

implementation of health care delivery and outreach program models that acknowledge patient realities and needs.

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