Status of HIV-infected patients classified as lost to follow-up from a large antiretroviral program in Southwest Nigeria

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Background

• Antiretroviral therapy (ART), if used appropriately, can improve the health of HIV positive individuals and prevent early death

• Sustained retention in care is essential in achieving the 90-90-90 targets

• Retention of care among patients enrolled in ART programs in sub-Saharan Africa is generally poor
• In the Lagos University Teaching Hospital (LUTH) antiretroviral programme, close to 50% of patients are classified as lost to follow up (LTFU)

• It is unclear if these patients have self- transferred, died or if there are other reasons for LTFU
Objectives

• To determine the rate of loss to follow up among adult patients registered in LUTH antiretroviral program within a five year period

• To determine rate of retention in care in other facilities among a sample of patients lost to follow up from the program

• To determine the factors associated with disengagement with care and willingness to re-engage in LUTH
Methodology

• **Study population**: Laboratory-confirmed HIV-infected adult patients LTFU who enrolled for care between January 1, 2010 and December 31, 2014.
  • Inclusion criteria: complete locator information
  • Exclusion criteria: confirmed deaths, known transfers, moved out of state

• **Study design**: Descriptive, retrospective, cross-sectional study
• **Definition of variables**
  - **LTFU**: not receiving any service in LUTH at least once within last 12 months from commencement of study (January 1 – December 31, 2016)
  - **Retention in care**: receiving continued HIV care in another clinic
  - **Disengagement from care**: not receiving HIV care

• **Data collection methods**:
  - **Secondary data**:
    - Locator information: Name, Address, Phone number
  - **Primary data**:
    - Community-based, interviewer-administered questionnaires
Primary data survey tool

OUTCOME STATUS OF PATIENTS LTFU

10. When last were you at APIN clinic? (month/year)
11. Why did you stop coming to the clinic? (Multiple responses allowed. Rank the top 3)
   a. High costs of transportation
   b. Clinic is too far
   c. The waiting time is too long
   d. I travelled
   e. I moved
   f. I started treatment in another clinic
   g. Afraid of scolding from clinic staff
   h. Attending clinic risks disclosure to community
   i. Staff was not nice
   j. Too many appointments
   k. Lack of privacy
   l. I am busy at work
   m. I am busy caring for family
   n. Attending clinic risks disclosure to family
   o. Family person does not approve of clinic
   p. I didn’t need ARVs
   q. I am feeling healthy
   r. My religion/faith does not permit me
   s. Other:

12. Were you ever placed on treatment with antiretroviral medicine in the clinic?
   a. Yes (Go to question 13)
   b. No (Go to question 18)

13. If yes, are you still using the medicine?
   a. Yes always (Go to question 14)
   b. Yes sometimes (Go to question 14)
   c. No (Go to question 15)

14. If yes, where do you get your medicine from? (Multiple responses allowed. Rank the top 3)
   a. My other clinic
   b. Pharmacy outside of clinic
   c. My spouse
   d. My friend
   e. Other (specify):

15. If no to Q14, why are you not using the medicine? (Multiple responses allowed. Rank the top 3)
   a. Suspected side effects of ARVs
   b. Very weak/sick
   c. Now on alternate medicine (specify)
• **Data analysis:**
  • Stata version 15.1
  • Chi-squared test for bivariate associations
  • Logistic regression for multivariate associations
    • Respondents’ characteristics vs. disengagement with care
    • Respondents’ characteristics vs. willingness to re-engage in LUTH
Ethical considerations

• Study posed a social risk
• Face to face interviews conducted at preferred locations of participants
• Written informed consent
• Assurance of confidentiality
• LTFU patients who were alive and no longer in care were referred
• For secondary data, participants had earlier given written consent
Results

Patients in clinic population = 6,108

Suspected LTFU = 3,397 (56%)

Tracing attempted = 1,803 (53%)

Successfully traced = 425 (24%)

Alive = 355 (84%)

Interviewed = 268 (75%)

Retained in care = 96 (36%)

Disengaged from care = 172 (64%)

Tracing not attempted = 1,594 (47%)

[Incomplete/missing locator information = 1,591 (99.8%), repeated names = 3 (0.2%)]

Not found = 1,378 (76%)

[Unavailable/inactive no./switched off = 1,159 (84.1%), wrong no. = 208 (15.1%), no response = 11 (0.8%)]

Dead = 70 (16%)

Not interviewed = 87 (25%)

[Out of state = 65 (74.7%), declined interview = 17, wrongly classified = 5 (5.8%), (19.5%)]
## Reasons for discontinuation of care

<table>
<thead>
<tr>
<th>Ranked first</th>
<th>Ranked second</th>
<th>Ranked Third</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travelled away (26%)</td>
<td>Long waiting time (20%)</td>
<td>Long waiting time (20%)</td>
</tr>
<tr>
<td>Distance to clinic (18%)</td>
<td>Distance to clinic (16%)</td>
<td>Distance to clinic (12%)</td>
</tr>
<tr>
<td>Moved to new home (13%)</td>
<td>Travelled away (12%)</td>
<td>Started care elsewhere (12%)</td>
</tr>
<tr>
<td>Feeling healthy (7%)</td>
<td>Started care elsewhere (8%)</td>
<td>High transport cost (11%)</td>
</tr>
<tr>
<td>Long waiting time (5%)</td>
<td>Busy at work (8%)</td>
<td>Staff not nice (10%)</td>
</tr>
<tr>
<td>Didn’t need ARV (4%)</td>
<td>High transport cost (7%)</td>
<td>Busy at work (8%)</td>
</tr>
</tbody>
</table>
More than half of the traced and interviewed LTFU cohort were not on ART
Reasons for stopping ART
N = 82

- Travelled: 32%
- Feeling healthy: 30%
- Exhausted ARV: 23%
- Not permitted by faith: 16%
- High transport cost: 15%
- Not wanting to take ART for life: 13%
- Work responsibilities: 10%
- On alternate medicine: 6%

Reasons for treatment gaps
N = 19

- Travelled: 47%
- Exhausted ARV: 37%
- High transport cost: 32%
- Work responsibilities: 26%
- Forgets to take ARV: 21%
- No work/no money: 10%

Respondents failed to take ART mostly because they travelled.
• The predictors of disengagement from care were not having started ART and longer duration in HIV care.

• The predictors of willingness to re-engage care at LUTH were male sex and being disengaged from care.

Majority (92%) of the respondents that were still on ARVs had a 100% adherence over the prior 7 days.

60% of respondents were willing to re-engage in LUTH.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>COR</th>
<th>AOR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disengaged from care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not started on ART (vs. Started on ART)</td>
<td>4.263</td>
<td>4.223</td>
<td>1.992 - 8.950</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Male sex (vs. Female)</td>
<td>1.884</td>
<td>1.711</td>
<td>0.965 - 3.033</td>
<td>0.066</td>
</tr>
<tr>
<td>Months in care before LTFU</td>
<td>1.009</td>
<td>1.009</td>
<td>1.004 - 1.014</td>
<td>0.001</td>
</tr>
<tr>
<td>Willingness to re-engage in program</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not started on ART (vs. Started on ART)</td>
<td>3.195</td>
<td>1.916</td>
<td>0.899 - 4.083</td>
<td>0.092</td>
</tr>
<tr>
<td>Male sex (vs. Female)</td>
<td>2.229</td>
<td>1.886</td>
<td>1.004 - 3.540</td>
<td>0.048</td>
</tr>
<tr>
<td>Months in care before LTFU</td>
<td>1.006</td>
<td>1.003</td>
<td>0.999 - 1.007</td>
<td>0.118</td>
</tr>
<tr>
<td>Disengaged in care (vs Retained in care)</td>
<td>12.176</td>
<td>9.289</td>
<td>4.994 - 17.276</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

COR: crude odds ratio; AOR: adjusted odds ratio
Reference categories: aRetained in care bNot willing to re-engage in program
Discussion

• The LTFU rate is high and similar to other studies in Africa
• Reasons for LTFU also similar
• ART decentralization, synchronization of care are key
• Those not on ART more likely to disengage from care - test and treat approach can help
• Increased motivation as patients stay longer in HIV care
• Limitation: Missing/incomplete/wrong locator information in secondary database
Conclusion

• Most of the interviewed cohort that was LTFU from LUTH were truly disengaged from care and not on ART

• Innovative interventions are required:
  • To improve retention in HIV care
  • To address processes of re-engagement of patients that are LTFU
Co-investigators

• Seema Meloni - mentor
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• Alero Roberts
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• Data officer LUTH APIN clinic: Hameed Adelabu
• Study participants
References

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THANK YOU