Failure to Engage as Key Factor of Loss to Follow-up from Care and Treatment Among HIV-Infected Children in Botswana: A Case-Control Study

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Background

- Loss to follow-up (LTFU) is a critical factor in determining clinical outcome in HIV treatment programs.
- Identifying modifiable factors of LTFU is fundamental for designing effective patient retention interventions.
- We analyzed factors contributing to children LTFU from a treatment program to identify those that can be modified.

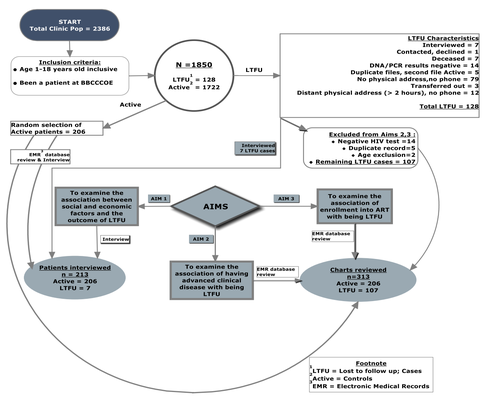
Objectives

The study objectives are to determine the factors that contribute to LTFU among HIV-infected children. Specifically, we wanted to evaluate:

1. Advanced clinical disease with relation to LTFU
2. Enrollment into ART status and relation with LTFU
3. Social and economic factors and relation with LTFU

Methods

- A Case-Control study involving 313 children was used to compare the socio-demographic and clinical characteristics of children LTFU (cases) with those remaining in care (controls) at a large pediatric HIV care setting in Botswana.
- We also traced children through caregiver contacts and those we found (n=213), we conducted structured interviews with the patients' caregivers.



Results

Demographic information and number of years enrolled in the BBCCCOE clinic of children 1-18 years old whose medical records were analyzed in case-control study, Botswana

	ALL Mean (SD) or n, %	Active Patients N = 206 (%)	LTFU Patients N=107 (%)	T-Test (2-sided)
Gender, N = 313				
Female	148 (47.3)	98 (47.6)	50 (46.7)	0.887
Male	165 (52.7)	108 (52.4)	57 (53.3)	
Age				
Mean, SD	10.8(4.5)	11.7 (4.0)	9.3 (4.9)	<0.01
< 5 year	38 (12.1)	16 (7.8)	22 (20.6)	<0.01
> 5 years	275 (87.9)	190 (92.2)	85 (79.4)	
Length of enrollment				
1 visit	53 (16.9)	2 (0.9)	51 (47.7)	<0.01
< 6 months	34 (10.9)	8 (3.8)	26 (24.3)	
> 6 months	226 (72.2)	196 (95.1)	30 (28.0)	

Clinical characteristics of children 5-18 years old whose medical records were analyzed in case-control study, Botswana

	ALL Mean (SD) or n, %	Active Patients N = 206 (%)	LTFU Patients N=107 (%)	T-Test (2-sided)
Baseline CD4 cell count classification				
Mild Immunosuppression (>350)	80 (69.6)	52 (73.2)	28 (63.6)	0.047
Advanced (200 – 349 cells/µL)	11 (9.6)	9 (12.7)	2 (4.6)	
Severe (<200 cells/µL)	24 (20.9)	10 (14.1)	14 (31.8)	
Absolute CD4 cell count				
Mean (SD)	679 (544)	673 (489)	691 (628)	0.872*
Duration of Clinic Attendance (n=275)				
Number with CD4 measures	115	71	44	
Duration in days (SD)	1489 (1260)	2160 (1082)	406 (604)	<0.01
Number without CD4 measures	160	119	41	
Duration in days (SD)	1044 (1000)	1350 (973)	157 (312)	<0.01
Viral Load (n= 275)				
Number with baseline viral load	94	52	42	
Mean (SD) baseline viral load (in logs)	5.10 (0.75)	4.92 (0.74)	5.33 (0.70)	<0.01
Number without baseline vial load	181	138	43	
WHO staging of HIV infection (n=249)				
I and II	101 (40.6)	84 (44.7)	17 (27.9)	0.024
II and IV	148 (59.4)	104 (55.3)	44 (72.1)	
Patient on ART (n=275)				
Yes	208 (75.6)	184 (96.8)	24 (28.2)	<0.01
No	67(24.4)	6 (3.2)	61 (71.8)	
Patient not on ART				
Mild (>350cells/µL)	56 (90.3)	5 (100.0)	51 (89.5)	1.00
Advanced (200 – 350 cells/µL)	2 (3.2)	0 (0.0)	2 (3.5)	
Severe (< 200 cells/µL)	4 (6.5)	0 (0.0)	4 (7.0)	
Length of enrollment	275	190	85	
Mean days (SD)	1325 (1936)	1653 (1086)	594 (2965)	<0.01
# of clinic visits			5	
1 visit	33 (12.0)	2 (1.1)	31 (36.5)	< 0.01
< 6 months	32 (11.6)	8 (4.2)	24 (28.2)	
> 6 months	210 (76.4)	180 (94.7)	30 (35.3)	

Results

Clinical characteristics of children aged < 5 years old whose medical records were analyzed in case-control study, Botswana

	ALL Mean (SD) or n, %	Active Patients N = 206 (%)	LTFU Patients N=107 (%)	T-Test (2-sided)
Patient on ART				
Yes	18 (47.4)	16 (100.0)	2 (9.1)	<0.01
No	20 (52.6)	0 (0.0)	20 (90.9)	
Length of enrollment	38	16	22	
Mean days (SD)	388.2 (529.6)	916.3 (421.8)	4.1 (10.2)	<0.01*
Duration of clinic attendance				
# with CD4% measures	17	11	6	<0.01
Duration in days (SD)	518 (480)	798 (363)	13 (18)	
# without CD4% measures	21	5	16	
Duration in days (SD)	283 (555)	1186 (454)	1 (0.0)	<0.01
# of clinic visits				
1 Visit	20 (52.6)	0 (0.0)	20 (90.9)	<0.01
< 6 months	2 (5.3)	0 (0.0)	2 (9.1)	
> 6 months	16 (42.1)	16 (100.0)	0 (0.0)	

Key Findings

- Children < 5 years were twice as likely as older children to be LTFU (20.6% versus 7.8% and 79.4% versus 92.2% respectively, p<0.01).
- Approximately half (47.6%, n=51) of LTFU patients failed to further engage in care after just one clinic visit, as compared to less than 1% (n=2) in the control group (p<0.01).
- Patients LTFU were more likely than controls to have advanced disease, greater immunosuppression, and not to be receiving Antiretroviral Therapy (ART).
- Among interviewed patient caregivers, psychosocial factors (e.g. stigma, religious beliefs, child rebellion, disclosure of HIV status) were characteristic of patients LTFU, but not of controls (data not shown).
- Socio-economic factors (e.g. lack of transportation, school-related activities, forgetting appointments) were cited predominantly by the controls as compared to the cases (data not shown).

Discussion

1. The patients who became LTFU were younger, more sick, and did not adequately engage with the facility/ care center. Coupled with the stigma associated with HIV/AIDS, it may have resulted in their becoming LTFU
2. Most patients who became LTFU did not provide adequate contact information during their initial visit, making it difficult for those intended to trace them.

Conclusion

- Pediatric patients and their caregivers need to be targeted and engaged at their initial visit, with special attention to children < 5 years.
- Possible interventions include providing psychosocial support for issues that deter patients from engaging with the clinic.
- Accurate contact information obtained at first clinic visit is crucial.
- Collaboration with community-based organizations focused on reducing stigma may be useful in addressing these complex issues.

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Providers' Perceptions of the Causes of Loss to Follow-up of HIV-Infected Children in Botswana

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Background

- Loss to follow-up (LTFU) in the care and treatment of HIV/ AIDS has been used to refer to patients failing to present for routine clinic evaluation for more than 180 days (6 months) since the last clinic visit [1,2,3,4,5].
- Studies of children LTFU are few, compared to documentation on adults.
- A good understanding of the reasons that lead to LTFU from HIV/AIDS care and treatment programs is important if we are to design effective retention interventions and is fundamental in evaluating the impact of the global ART scale-up [1].
- Ideally, the LTFU patients and their caregivers are the best source of information about LTFU through personal interviews, however, the process of tracing these patients isn't always successful.
- Healthcare providers (nurses, physicians, and social workers), by virtue of their experiences in interacting with HIV-infected children and their caregivers, are an important source of information on the causes of loss to follow-up (LTFU).

Objectives

❖ To explore perceptions of healthcare providers regarding factors that lead to pediatric HIV-infected patients becoming lost to follow up from care an treatment.

Methods

- Study was conducted at a large pediatric HIV clinic in Gaborone, Botswana and involved conducting in-depth interviews with clinical staff (n=10) consisting of nurses, social workers and physicians.
- All staff involved in In-Reach program, that follows patients experiencing clinical and psychosocial difficulties, were interviewed
- We conducted interviews to gain understanding of clinical health workers' perceptions and experiences in dealing with LTFU problems and possible solutions as perceived by the healthcare providers.

Key Findings

- ***Pill fatigue, rebellion and decreased caregivers' support cascade*** – the children and adolescents are 'tired' of taking medication; those who are older continue to wrestle with denial and stigma of HIV, leading to rebellion in their teenage years. Lack of continued caregiver support in those moments compound the situation, leading to LTFU
- ***Parental religious beliefs of being healed***, and by extending it to the child, effectively interfering with child's treatment program
- ***Communication breakdown, unreported deaths and transfer outs*** – lack of clear communication between the child's family and the clinic at initial engagement, to any circumstantial changes
- ***Need for personalized counseling and additional screening for depression*** – there are missed opportunities for specific individuals when treatment adherence sessions are held as group sessions

Quotable Quotes

"*…There are parents who just neglect; they don't care…they have no valid reasons why they are not bringing their children* [*to clinic*]."

—A nurse interviewee, describing experience with some parents of children who miss appointments

- *"Because HIV does not have a cure at the moment, many people are looking for solutions of where they can find a cure. Some churches claim to spiritually heal people from HIV, so some of our parents who attend these churches believe they are healed and stop coming …so we have instances of the child not knowing their [HIV] status but defaulting because of the parent or the caregivers…who say because I have been healed, I have gone for deliverance, I am not going there [to the Clinic] and also my child is not going there"*.

—A male doctor interviewee, describing a parent's religious conviction and whose child has stopped coming to the Clinic

- *"During adherence classes, not everyone will ask questions. But when you go to their homes [*in an effort to trace them and find out why they no longer come to clinic*], they will start raising issues, because now it is personal…one to one…they are free to open up and say that I have a problem with this, or am questioning this, or my doubts are here. And then you clarify those things that you said in the adherence classes… and now they are free to come again"*

—A social worker interviewee, describing a LTFU patient successfully traced and reintroduced back to care

Discussion & Conclusion

- Health workers underscored the psychosocial nature of the issues of LTFU and the need to develop a more holistic approach to treating HIV-infected children.

Reference

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