# Ugwu OR

# CC –BY

# Impact of a child -friendly clinic on retention of HIV-infected children in care: an intervention study

DOI:http://dx.doi.org/10.4314/njp.v44i4.1

Accepted: 22nd August 2017

Ugwu OR ( )
Department of Paediatrics,
University of Port Harcourt
Teaching Hospital Port Harcourt

**Abstract:** Background: Certain researchers have reported that a child-friendly clinic may improve patient/caregiver satisfaction at clinic attendance. This could serve as an innovation for reducing loss-to-follow up and increasing retention in care.

Aim: To assess the impact of making the clinic more child-friendly on clinic experience, retention in care and loss-to-follow up of HIV -infected children.

Method: The study was carried out in three phases. Phase one was a satisfaction survey to find out the patient/caregivers' satisfaction of the clinic environment and services provided using a self-administered questionnaire. Phase two was the creation of the child-friendly environment and phase three was a post-provision of child-friendly clinic satisfaction survey. The loss-to-follow up rate (failure to return to clinic

3months after the last scheduled clinic appointment in a child not known to be dead or transferred out of the facility) and retention rate (remaining alive and receiving highly active antiretroviral therapy) were also determined before and after setting up the child-friendly clinic.

Results: There were 146 respondents before the study and 206 respondents after the intervention. The retention rate increased from 62.5% to 82% (p=0.02), while the loss-to-follow up rate dropped from 27.7% to 7.0% (p=0.00).

Conclusion: Making the clinic area child-friendly can impact greatly on HIV care by improving patient satisfaction and retention of HIV-infected children in care and reducing loss-to-follow up.

**Key words:** HIV, child-friendly environment, retention in care, loss to follow-up.

## Introduction

HIV is a lifelong illness. This means that children in care and treatment have to access health facilities frequently. This therefore implies that they may miss some school days, explorative and play activities which are necessary for their intellectual and cognitive development.<sup>1</sup>

Once an HIV-infected child is diagnosed and linked to care, retention in care becomes necessary in order to optimize treatment outcome. In resource-limited settings, patient retention poses a serious challenge to

effective treatment of HIV-infected persons. Fox and Rosen<sup>2</sup> estimated 36-month retention at 65% in Africa. For patients on antiretroviral therapy (ART), retention in care is critical in order to prevent medication interruptions, maintain immunologic benefits, prevent HIV resistance, monitor drug toxicity and clinical HIV disease progression as well as to identify and treat any new opportunistic infections that may occur.<sup>3</sup> For patients yet

to be initiated on ART, retention in care is also vital as it ensures provision of prophylactic medications for opportunistic infections, and prompt initiation of ART once indications arise. Patients actively engaged and retained in care are more likely to receive and adhere to prescribed antiretroviral medication, achieve viral suppression, and ultimately improve survival. Non-adherence to medical appointment was found to be an important risk factor for treatment failure. Retention in care is thus an important element of clinical success for both the patient and the overall effectiveness of the ART program.

Apart from distance, costs of transportation, <sup>3,9,10</sup> and social stigma, <sup>10</sup> an unfriendly clinic environment with negative clinic experience can also be a barrier to retention in care. <sup>10</sup> Often children are frightened by activities in clinics, which make clinic visits very unpleasurable. This therefore necessitates creating innovations in the provision of care for children in order to improve clinic

experience.

A child-friendly environment (which is a protected space where a child feels both physically and emotionally secure and at ease)<sup>11</sup> helps to reduce the fear, anxiety and distress often associated with clinic visits. The children will be able to spend waiting time doing enjoyable things thus making clinic visits pleasurable. In having positive experiences with the clinics, parents are encouraged to bring their children regularly for scheduled out-patient clinic visits thereby enhancing retention in care.

Only very few researches have reported the impact of a child friendly clinic on the retention in care of HIV-infected children. The aim of this study was to assess the impact of making the clinic more child-friendly on clinic experience, retention in care and loss to follow up of HIV-infected children.

#### **Material and Methods**

The study was done in the Consultant Paediatric Clinic of the University of Port Harcourt Teaching Hospital and was carried out in three phases. In order to objectively assess the impact the study will have on the users, a satisfaction survey was done during phase one (over a period of 3 months before the intervention) using a pretested self-administered questionnaire (for those literate enough to read and write) and interviewer-administered (for those who cannot read or write) to find out the caregivers' satisfaction of the clinic environment and services provided. Tracking of patients was also done by either the expert clients (volunteer mothers of HIV-infected children) through home visitation or the doctors through phone communication.

Phase two was the creation of the child-friendly environment. The clinic area was painted with artistic drawings in child-friendly colours with the common cartoon characters. More seats were provided for both parents and children. Educational materials including story books, writing materials, crayons, encyclopedia, activity materials and toys were provided for the different age groups (Fig. 1A and B). The children were allowed to play freely under direct vision of the parents and nurses. The expert clients also gave health talks to the children and engaged them in healthy debates on health related issues and group plays/activities. A video entertainment was also provided and was used as an opportunity to train the young minds on positive behaviours. In addition, the child's school schedule was taken into account when booking for clinic appointments (most appointments were put during midterm break and holidays [3-4 monthly on average] and exam periods avoided as much as possible).

Phase three was another clinic satisfaction survey (done over three months) after the provision of the childfriendly environment. Responses before and after the provision of the child-friendly environment were compared. The loss to follow up (LTFU) and retention rates were determined before and after setting up the child-friendly clinic. This was calculated from the register of all children and adolescents who have been enrolled to receive care and treatment before and after the intervention. Only HIV-infected children who have been initiated on ART were included. HIV exposed infants whose status is not known were excluded from the study. A patient was considered LTFU if he/she has failed to return to clinic 3 months after the last scheduled clinic appointment and is not known to be dead or transferred out of the facility. Retention was defined as remaining alive and receiving highly active ART (i.e not registered as deceased, transferred out or LTFU) at the paediatric infectious disease clinic using clinic visit dates.

The retention rate was calculated as: <sup>12</sup>
Number of patients alive and on ART X 100
No. of patients alive and on ART +
No. of patients who have died +

No. of patients that are LTFU

Data were analysed using the Statistical Package of Social Sciences (SPSS) version 15. Chi-square test (and Fisher's exact test where applicable) were used as tests

of statistical significance and a p-value of <0.05 was considered as significant.

#### Results

A hundred and forty six caregivers/adolescents responded before the study while there were 206 respondents after the creation of the child friendly clinic. Majority of the children had been receiving care and treatment in the facility for over three years.

On the child friendliness of the facility (Table1), 88 (60.3%) responded that the accessibility of the waiting area was fair or poor, 93 (63.7%) described the level of comfort as being fair or poor while only 62(42.5%) responded that the clinic facility was child friendly before the renovations and adjustments to improve the clinic environment. On the other hand, 206 (100%) of the respondents rated the accessibility of the waiting area for the children as being excellent or good, 206 (100%) felt that the overall level of comfort of the waiting area for the child and the child friendliness of the facility was also excellent or good after the intervention.

Before the intervention, majority 93(63.7%) complained that the sitting arrangement in the clinic was inadequate while 86(58.9%) felt that the level of cleanliness was not good. After the scaling up of facilities at the clinic, there was a significant improvement in the responses as 206 (100%) responded that seats were now adequate and all 206 (100%) agreed that the level of cleanliness had improved. Both before and after the scaling-up of clinic facilities, majority 132(90.4%) and 206(100%) respectively agreed that opportunities for learning and relaxation should be provided for the children in the clinic.

On the willingness to continue treatment at the facility,

before the renovation to improve the clinic environment, 66 (45.2%) were not willing to come back based on their past experiences. On the other hand after the renovation, all 206 (100%) were very willing and happy to continue their child's treatment in the facility based on the remarkable improvement they had seen and would recommend the facility to other members of the public. The improvements in the responses after provision of the child-friendly service environment were all significant (p=0.00).

Before the study, a total of 301 children/adolescents had been enrolled to receive care and treatment at the facility out of which 72 met the LTFU criteria giving a LTFU rate of 27.7% (Table 2). After improvement in the clinic facility, 378 had been enrolled in the register. Eight (11%) patients who were LTFU had been successfully tracked and returned to care, 37 (51%) returned on their own while 4 (6%) reappeared because they were ill. None of them was receiving any care or treatment elsewhere. Twenty-three were still lost to follow up. The LTFU rate significantly dropped to 7.0% (p=0.00), while the overall retention rate significantly increased from 62.5% to 82% (p=0.02).

<b>Table 1:</b> General assessment of the patient/caregivers' satisfaction and child friendliness of the clinic environment			
Parameters	Before	After	p-value
Assessed	No. (%)	No. (%)	
Total	146	206	
Accessibility of	the waiting area:		
Excellent	13(8.9)	155 (75.2)	
Good	45(30.8)	51 (24.8)	
Fair/Poor	88(60.3)	0 (0.0)	0.00
Level of comfort	t:		
Excellent	8(5.5)	188 (91.3)	
Good	45(30.8)	18 (8.7)	
Fair/Poor	93(63.7)	0 (0.0)	0.00
Level of cleanling	ness of waiting are	ea:	
Excellent	7 (4.8)	153 (74.3)	
Very Good	53 (36.3)	53 (25.7)	
Fair/Poor	86 (58.9)	0 (0.0)	0.00
Child friendline	ss of the facility:		
Excellent	13 (8.9)	121 (58.7)	
Good	49 (33.6)	85 (41.3)	
Fair/Poor	84 (57.5)	0 (0.0)	0.00
Need for Oppor	tunities for		
learning and rei	laxation:		
Agree	132 (90.4)	206 (100)	
Indifferent	12 (8.2)	0(0.0)	
Disagree	2 (1.4)	0(0.0)	0.00
Willingness to c	ontinue		
treatment at the	facility:		
Willing	80 (54.8)	206 (100)	
Not willing	66 (45.2)	0(0.0)	0.00

Table 2: Retention and loss to follow-up rates before and after making the clinic more child-friendly Parameters **Before** After p-value No. No. Cumulative No. of enrolled children 301 378 Total No. lost to follow up 72 23 Cumulative No. of deaths 41 45 7.0% 0.00 Loss to follow up rate 27.7% 82.0% Overall Retention rate 0.02

## Discussion

Retention in HIV care has been defined by WHO as continuous engagement from diagnosis, initiation on ART and retention in lifelong ART care. <sup>13</sup> This implies that the individual remains connected to medical care once enrolled, and is able to adhere to critical aspects of care including attendance of regular follow-up appointments as prescribed by a health care provider. <sup>9</sup>

Although care and treatment programs in resource-limited settings have reached millions of HIV-infected patients, retention in care is a critical but challenging aspect of efforts to optimize patient outcomes. Poor retention can range from missing a single scheduled clinic visit to outright loss-to-follow up (failure of a patient not known to have died to present to clinic for a certain period of time). A review of 33-patients cohort studies taking ART in 13 African countries suggested that only 60% of patients remain enrolled in programs after 2 years, LTFU accounting for 56% of all attrition. In a retrospective cohort study of HIV-infected children and adults attending an ART clinic in Ethiopia, the prevalence of LTFU from ART was 26.7%. This was comparable to the LTFU rate in the present study.

The retention rate in this study was 62.5% before the interventions to retain patients in care. This was similar to the findings in other reports in studies in sub-Saharan Africa.<sup>2</sup> A number of studies have sought to understand the determinants of retention through identifying factors associated with poor retention.<sup>10</sup> Apart from distance, transportation cost,<sup>3, 9, 10, 16</sup> stigma<sup>10, 17</sup> and tight work schedules, an unfriendly clinic environment can pose a great challenge to retaining patients in care in resource-limited settings.<sup>10</sup> Retention in care is thus influenced not only by socioeconomic factors of the patient, but also by external factors like the health system (including clinic environment, care providers and supporting services).<sup>9</sup>

Goals to improve retention could be divided into those that reduce patient costs (e.g. making it easier to access care financially) and those that increase patient benefits (e.g. improving quality of services). In a meeting on retention in HIV Programmes by WHO, one of the areas identified as potentially important in improving services and retention of children and adolescents in care was provision of child- and adolescent- friendly clinic schedules. This was corroborated in this study as the children and their caregivers were significantly more satisfied (and more willing to continue care) and the retention rate significantly improved to 82% after making the

clinic more child-friendly. Satisfaction with the clinic experience predicts whether or not patients return for care. Children who enjoy their visit are usually more willing to come back for follow-up. Among people living with HIV, satisfaction with care has been shown to positively influence retention in HIV care and adherence to ART. Patients who were not retained in care may have been less satisfied with their clinic experience and for that reason did not return for scheduled appointment visits. In Uganda, scaling up paediatric HIV care through many programs that included creating child-friendly service environments was very important in maximizing paediatric capture and parents' satisfaction.

Lee *et al* <sup>20</sup> examined the association between availability of youth friendly services and retention in HIV care and reported that youths living with HIV were more likely to be retained in care at clinics with a youth-friendly waiting area. In the study by Yehia *et al*, <sup>10</sup> participants in both groups (retained and not retained in care) identified presence of social support, patient-friendly clinic services and positive relationships with providers and clinic staff as facilitators to retention in HIV care.

When children have a pleasurable clinic experience, parents are likely to appreciate it and are more likely to tell their friends about the child friendliness of the clinic. This will encourage other members of the community to access care in the facility. This may have accounted for the large numbers of children who returned on their own after making the clinic more child-friendly.

#### Conclusion

Making the clinic area child-friendly was associated with improving patient's satisfaction and retention of HIV-infected children in care and reducing loss to follow-up. Given the difficulty in identifying and linking patients to care, we cannot afford to lose them once engaged in care. There is need to carry out a regular satisfaction survey in order to identify areas in the services that have gaps that needs to be filled in order to improve access and sustain retention in care. More attention needs to be given to finding the patients who miss scheduled clinic visit (using the most cost-effective methods) before they become LTFU.

**Conflict of Interest:** None **Funding:** None

## Acknowledgement

The author is grateful to all the children and their parents for their participation in helping to improve HIV care and to Clinton Health Access Initiative (CHAI) for providing the funds for the educational materials and patient tracking.

# References

- 1. Cummins SK, Jackson RJ. The built environment and children's health. *Pediatr Clin North Am 2001; 48(5):1241–52.*
- Fox MP, Rosen S. Retention of adult patients on antiretroviral therapy in low- and middleincome countries: Systematic review and meta-analysis 2008-2013. JAIDS 2015;doi10.1097/ QAI. 00000000000000553
- Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, et al. Retention in care among HIVinfected patients in resourcelimited settings: Emerging insights and new directions. Curr HIV/AIDS Rep.2010;7(4):234-244.
- 4. Xia Q, Kersanske LS, Wiewel EW, Braunstein SL, Shepard CW, Torian LV. Proportions of patients with HIV retained in care and virally suppressed in New York City and the United States: Higher than we thought. JAIDS 2015;68(3):351-8.
- Giordano TP, Gifford AL, White Jr. AC, Suarez Almazor ME, Rabeneck L, Hartman C, et al. Retention in care: A challenge to survival with HIV infection. Clin Infect Dis 2007; 44 (11): 1493-9.
- Berg MB, Safren SA, Mimiaga MJ, Grasso C, Boswell S, Mayer KH. Non-adherence to medical appointments is associated with increased plasma HIV RNA and decreased CD4 cell counts in a communitybased HIV primary care clinic. AIDS Care 2005;17(7):902-7.

- Lucas GM, Chiasson RE, Moore RD. HAART in a large urban clinic:Risk factors for virologic failure and adverse drug reactions. *Annals* of Internal medicine 1999;131 (2):81-7.
- 8. Rasteger DA, Fingerhood MI, Jasinski DR. Highly active antiretroviral therapy outcomes in a primary care clinic *AIDS Care* 2003;15(2):231-7.
- 9. Patel A, Hirschhorn L, Fullem A, Ojikutu B, Oser R. Adult adherence to treatment and retention in care. 2010; Arlington VA: USAID/ AIDSTAR-ONE PROJECT, Task Order 1
- Yehia BR, Stewart L, Momplaisir F, Mody A, Holtzman CW, Jacobs LM, et al. Barriers and facilitators to patient retention in HIV care. BMC Infect Dis. 2015; 15: 246.

- 11. UNICEF. A practical guide to developing child friendly space. Available at http://cpwg.net/wpcontent/uploads/sites/2/2011/09/A\_Practical\_Guide\_to\_Developing\_Child\_Friendly\_Spaces\_\_UNICEF\_11.pdf (accessed February 27, 2015).
- 12. Assefa Y, Lynen L, Wouters E, Rasschaert F, Peeters K, Van Damme W. How to improve patient retention in an antiretroviral treatment program in Ethiopia: a mixed-methods study. *BMC Health Services Research* 2014;14:45 DOI: 10.1186/1472-6963-14-45.
- 13. World Health Organization. Retention in HIV Programmes; defining the challenges and identifying solutions; Meeting Report 13-15; 2011;1-64.
- 14. Rosen S, Fox MP, Gill CJ. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: A systematic review. *PLoS Medicine 2007;4* (10):e298.

- 15. Berheto TM, Haile DB, Mohammed S. Predictors of loss to follow-up in patients living with HIV/AIDS after initiation of antiretroviral therapy. *N Am J Med Sci. 2014*; 6(9): 453–9.
- 16. Tuller DM, Bangsberg DR, Senkungu J, Ware NC, Emenyonu N, Weiser SD. Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: a qualitative study. AIDS Behav. 2010;14(4):778-84.
- 17. McGuire M, Munyenyembe T, Szumilin E, Heinzelmann A, Le Paih M, Bouithy N, et al. Vital status of pre-ART and ART patients defaulting from care in rural Malawi. Trop Med Int Health. 2010 Jun;15 Suppl 1:55-62.
- 18. Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC, Giordano TP. Examining the link between patient satisfaction and adherence to HIV care: a structural equation model. *PLoS ONE*. 2013;8(1):e54729. doi: 10.1371/journal.pone.0054729.
- 19. Luyirika E, Towle MS, Achan J, Muhangi J, Senyimba C, Lule F, *et al.* Scaling up paediatric HIV Care with an integrated, family-centred approach: An observational case study from Uganda. PLoS One. 2013; 8(8): e69548.
- Lee L, Yehia BR, Gaur AH, Rutstein R, Gebo K, Keruly JC, et al. The Impact of youthfriendly structures of care on retention among HIV-Infected youth. AIDS Patient Care STDS. 2016 Apr;30(4):170-7.