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Keywords:	HIV, Children, Enablers, Retention, Care

SCHOLARONE<sup>™</sup> Manuscripts

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# Abstract

*Background:* Nigeria has the highest burden of paediatric HIV infection and the success of control efforts in the country is crucial to the global control of the HIV epidemic. However, defaults from schedules of care poses a threat to paediatric HIV control in Nigeria. This study was conducted in a pioneer facility for the implementation of the National HIV Prevention and Treatment Programmes.

*Objective:* To explore factors that facilitate adherence to clinic appointments from perspectives of child caregivers and service providers.

*Methods:* This is a qualitative study using in-depth face-to-face interviews conducted in 2016. Thirty-five participants were purposely sampled to comprise types of caregivers of HIV exposed/infected children receiving care and from categories of service providers. The interviews were audio recorded, transcribed, thematically analysed and presented using a socio-ecological model.

*Results:* The themes that emerged from participants' narratives included advanced education, affluence and residing close to the clinic at the intrapersonal level. Stable family dynamics and

support, HIV status disclosure and being a biologic parent or grandparent as caregiver emerged at the interpersonal level. At the community level, disclosure and support were identified, while at the health facility level positive staff attitude, quality of healthcare as well as peer support group influence were factors identified to facilitate regular clinic attendance.

*Conclusion:* The factors that enable retention of children in care are multidimensional and intricately connected. Programme improvement initiatives should include regular assessment of clients' perspectives to inform implementation of strategies that could reinforce caregiver confidence in the health system.

*Key words: HIV*, *Exposed*, *Infected*, *Children*, *Adherence*, *Enablers Antiretroviral*, *Clinic care*, *Perspectives*, *Caregivers*, *Care providers*,

#### Introduction

Poor retention in HIV care is a worldwide phenomenon and occurs across all the stages of the continuum of HIV care. It is however, more common in the paediatric sub-population and in sub-Saharan Africa (SSA).<sup>1</sup> The consequences of poor retention include resistance to antiretroviral drugs (ARVs), treatment failure and loss of the opportunity for smooth transition from the paediatric to adult clinic.<sup>2</sup>

In Nigeria, the latest retrospective cohort study on LTFU within the PMTCT care cascade showed that 37% of HIV-exposed children were already lost before the first infant visit at four weeks after delivery.<sup>3</sup> More disturbing is the fact that poor retention has been reported even from centres where active tracking of defaulters is carried out<sup>4</sup>, and from resource-rich settings.<sup>5</sup>

Understanding barriers to retention and addressing them will therefore go a long way in ensuring the retention of HIV-infected children within care which will improve the overall child survival. In Nigeria, few studies have been conducted to explore the reasons for retention of children within HIV care, particularly from the caregivers' perspectives. This is despite the fact that prior studies outside Nigeria have shown that caregiver's satisfaction is important for retention within HIV care.<sup>6</sup>

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#### **Material and Methods**

### Study design

A qualitative study design was used because It enables exploration of the complex interaction between social structure, behaviour, and culture as well as the factors that underpin them.<sup>7</sup> The study framework was based on the social ecological model, which defines behaviour as being influenced at different levels.<sup>8</sup> For the purpose of this study, the reasons for retention will be categorized at the intrapersonal, interpersonal, community, and healthcare system levels, as shown in Figure1 below.

# Study Setting and Hospital Guidelines

Zaria has a total population of 406,990 which is predominantly young.<sup>9</sup> The ancient walled city of Zaria and its immediate surroundings are largely dominated by Muslim and Hausa-Fulani culture. However, outside this place, the presence of many federal institutions, including two military barracks, have drawn people from all walks of life, giving Zaria a cosmopolitan outlook. This has led to the presence of clusters of high-risk areas for the transmission of HIV, as well as a social setting with diverse traditional and cultural beliefs and perceptions.

The study was conducted at the paediatric HIV clinic of ABUTH, Zaria. It has a large catchment area with patients attending from many states in northern Nigeria. A retrospective review of the clinic attendees for a period of eight years (2008-2016) has revealed the total number of children enrolled into the Clinic as 454, with age ranging from zero to 14 years and a male-female ratio of 1.27:1. By the end of December 2016, 239 were lost to-follow-up (LTFU), giving a cumulative LTFU rate of 52.6%.<sup>10</sup>

# Sample size and sampling

The overall sample size was 38 when saturation was attained. Sampling was Purposive and the study population comprised the different categories of the service providers and caregivers.

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Data collection was by individual, face-to-face, in-depth interviews. The Calgary-Cambridge framework for physical interviews was utilized. It goes through the stages of creating rapport,

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- Familiarization with the data through reading and, re-reading transcripts and listening to the recorded interviews repeatedly.
- The coding framework was then formed deductively, through the generation of codes originating from the topic guide, and inductively, through emerging themes.
- Coding of transcripts was performed manually
- The data was then charted into thematic matrices and interpreted.

The generated themes were pooled and integrated into common themes based on which the results were organised.<sup>12</sup>

### Ethics

The approval of the research and ethics committee of ABUTH, Zaria was obtained

### Aim

To explore the enablers to retention in the paediatric HIV clinic of ABUTH, Zaria, Nigeria.

### Results

The enablers to retention were categorized at the intrapersonal, interpersonal, community, and health care system levels, as shown in Figure 3.

# Demographic profile of participants

# Enablers to clinic attendance

#### Intrapersonal level

"The clinic is very important, because ....., once he starts taking the drugs, [....] he will stop falling sick frequently"

Service providers felt that having a biological parent and the grandparents as caregivers is an enabler to clinic attendance as opposed to guardians. They were perceived to be more involved in the care of the child.

"... if they are biologically related to the child like the parents, they tend to be more involved in the care of the child, you will be able to discuss a lot of issues with them [...] ... "

### **Interpersonal level**

Good family dynamics was perceived to be a facilitator to retention in clinic. In the same vein, support from the family both psychological, material, and even bringing the child to the clinic itself emerged as a strong motivator.

"..., my husband supports me a lot, he is negative, but he will bring us (herself and her child) to the clinic with his car, park his car, and wait for me for as long as I am in the clinic, and afterwards he takes me back home"

#### **Community level**

Support from members of the community emerged as a strong reason for retention in clinic. Many of the participants expanded on this to include support such as aiding the caregivers with money for transport, and supporting children, particularly orphans, with food, clothing and so on.

"Some people in the community use to help with transport money......",

However, the fear of discrimination has hindered the ability of some caregivers to access this support from the members of their community because of stigma.

Disclosure to trusted members of the family and community was similarly perceived to be an enabler to clinic attendance.

"It is good if you have somebody you trust to tell him/her about the status of your child because, in the event that you die before the person, she/he will be able to take care of your child's clinic requirements"

#### Health care system

Locating the clinic away from the main hospital provides privacy, which facilitates clinic attendance. Participants also felt that the cleanliness and spaciousness of the clinic, coupled with air-conditioned consulting rooms, makes attending the clinic comfortable and encourages retention.

"... There is confidentiality...and the rooms are well air conditioned, so the doctor and the patient are all comfortable"

Positive staff attitude to caregivers emerged as a strong motivator for remaining attached to the clinic. This was perceived by the caregivers as kind words, respect, and politely correcting them when they erred.

"What we love when we bring our children is to be shown sympathy..., perhaps the child is an orphan, so when the mother comes, she should be treated kindly, they should not shout at her"

In addition to giving the ARVs free, other incentives such as breast milk substitutes and mosquito nets emerged as major reasons for retention in the clinic.

"In those days when we started newly there were little things they used to give us, things like mosquito net, water guard..., I think it can also encourage attendance at the clinic"

Participants felt that a high standard of care was an important motivator for retention in clinic. Quality was felt to have a range of dimensions, including waiting times, skills and knowledge, availability of support services and a flexible patient-centred approach to care. They cited qualified, professional staff, availability of laboratory services, availability of drugs, and prompt

attention, as reasons for retention. Having integrated services in a clinic and giving the same appointment date for caregivers who are HIV positive and their children were the other enablers that related to the standard of care.

'Some prefer to come here regardless of the distance because the services here are better... in those other places, they will tell you that they have taken your blood to another place for test[ting], but here they do everything and you see your result'

The presence of a peer support group in the clinic for the caregivers was perceived as an enabler for clinic retention. Many participants elaborated on this citing the benefits of the support group such as psychological support, helping to combat stigma, material gains, and finding marital partners.

"The support group provides them with the opportunity to interact with one another, learn vocational skills; some have met new partners, and some have even been employed in the clinic

here"

Proactive tracking of defaulters by clinic staff was seen as an important reason for retention.

"It will help if those that have stopped coming are followed to their homes and counselled, they will understand, return and continue to take their drugs"

Interestingly, false notions surrounding the continuity of free ARVs have made some caregivers regular with their clinic attendance. This was out of the fear that, very soon the drugs will cease to be free and they will have to be buying.

"I heard that American people say they will stop giving drugs, so I don't want to stop coming to clinic so that the little I have will sustained me before I [have to] start buying when they stop [being free]

#### Discussion

Incentives given at the clinic such as transport money and food emerged as a strong enabler to retention. This is consistent with the finding from Kinshasa in the Democratic Republic of Congo, where conditional cash transfers increased retention in clinic within the PMTCT programme by 7.8 %.<sup>13</sup> This has also been corroborated in a systematic review on improving linkage and retention in HIV care.<sup>14</sup>

Good relationship between a caregiver and her/his spouse was found to be an important reason for retention in clinic. This echoes the finding from the latest qualitative synthetic review on the reasons for retention in SSA. The review showed that a good relationship between a couple leads to social normalization with the HIV situation and improved clinic retention.<sup>15</sup>

The larger family support, including support from siblings, was found to be important in ensuring retention to care. This agrees with the American Academy of Paediatrician's definition of the family as the primary source of strength and support for the child.<sup>16</sup> It is also consistent with a study in South Africa.<sup>17</sup> It was therefore not surprising that disclosure of the status of the child to close family members and a trusted few in the community was found to be an important enabler to retention in care. This was similarly reported from five HIV care centres across Nigeria<sup>18</sup>, and from across the West African sub-region.<sup>19</sup>

Parent and grandparent caregivers were associated with better retention. this could be related to the fact that the orphans have the added vulnerability of missing parental support. Studies have shown the retention of HIV-infected orphans to be worse than that of the children whose parents are still alive.<sup>20</sup>

Support from the wider members of the community was found to be an important enabler to retention, consistent with the findings from Ethiopia<sup>21</sup> and Zimbabwe.<sup>22</sup> Nonetheless, the availability of the support to the caregivers was limited by perceived stigma in the community. This is consistent with the findings from Ethiopia.<sup>21</sup>

The study found that a clean, spacious, well-ventilated clinic, with recreational facilities was a reason for retention in the clinic, as substantiated in the literature.<sup>23</sup> Friendly staff attitude to caregivers was found to be a strong facilitator to retention as was found in Tanzania.<sup>24</sup>

Tracking of defaulter's increases retention partly because it encourages re-engagement, and because some clients prefer to come to the clinic to avoid being traced via home visits for fear of disclosure of their status. This agrees with the study in Kenya.<sup>25</sup> The study additionally found that the caregiver support group in the hospital was a reason for retention, as was also found in Vietnam.<sup>26</sup>

**Conclusion and Recommendations** 

1. Quality improvement initiatives in the clinic should ensure a periodic and systematic capture of caregiver and patient perspectives on quality.

 2. The clinic managers could consider introducing incentives such as transport fares generally, and specifically identifying and assisting the orphans.

### References

- 1. World Health Organization. *Global update on HIV treatment 2013*. Available at: http://www.who.int/hiv.pub,mtct/strategic\_vision.pdf. (Accessed: 20 May 2015).
- Bangsberg DR, Kroetz DL & Deeks SG. Adherence-resistance relationships to combination HIV antiretroviral therapy. *Curr HIV/AIDS Rep.* 2007;4(2):65–72.
- Rawizza HE, Chang CA, Chaplin B, Ahmed IA, Meloni TO, Banigbe B, et al. LosstoFollow-Up within the Prevention of Mother-to-Child Transmission Care Cascade in a Large ART Programme in Nigeria. *Current HIV Research*. 2015;13(3):201-209.
- Wettstein C, Mugglin C, Egger M, Blaser N, Vizcaya LS, Estill J, et al. Missed opportunities to prevent mother-to-child-transmission: a systematic review and metaanalysis', *AIDS*, 2012;26(18):2361–2373. doi:10.1097/QAD.0b013e328359ab0c.
- Gerver S, Chadborn T, Ibrahim F, Vatsa B, Valerie C, Delpech VC et al. HIV-Positive Patient Retention in the UK: High Rate of Loss to Clinical Follow-Up among Patients from a London Clinic. *Journal of the International AIDS Society*. 2010; 13:29. doi: 10.1186/1758-2652-13-29.
- Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC & Giordano. Examining the Link between Patient Satisfaction and Adherence to HIV Care: A Structural Equation Model. *PLoS ONE*. 2013;8(1):54729. doi:10.1371/journal.pone.0054729.
- Green J. & Thorogood N. *Qualitative methods for heath research*. London: Sage Publications. 2013. Available At:https://uk.sagepub.com/engb/eur/qualitativemethods-for-health-research/book239018#contents. (Accessed: 8 July 2016).

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8.	McLeroy KR, Bibeau D, Steckler A. & Glanz K. An ecological perspective on health
	promotion programs. <i>Health Education Quarterly</i> . 1988;15(4):351-377.

- National Population Commission Abuja. Legal Notice and Publication of Details of the Breakdown of the National and State Provisional Totals of 2006 Census Federal Government of Nigeria Official Gazette: No. 24 Vol. 94. Available At: http://allafrica.com/stories/200705241002.html (Accessed: 10 June 2016).
- 10. Umar LW, Musa S, Abdullahi FL, et al. Trends in Loss-to-follow-up at a Tertiary Paediatric HIV Treatment Centre in Northern Nigeria. *Presented at the Joint UNAPSA/PAN International Conference, Abuja, Nigeria, January 2018.*
- 11. Kurtz S, Silverman J, Benson J, Draper J. Marrying Content and Process in Clinical Method Teaching: Enhancing the Calgary-Cambridge Guides. *Acad Med*, 2003;78(8):802-9.
- Ritchie J, Spencer L. & O'Connor W. (b). 'Carrying out Qualitative Analysis. In: Ritchie, J. & Lewis, J. (eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* Wiltshire, UK: SAGE Publications, 2003:219262.
- Yotebieng M, Thirumuthy H, Moracco KE, Edmonds A, Tabala M, Kawande B, et al. Conditional cash transfer to increase retention in PMTCT care, antiretroviral adherence, and postpartum virological suppression: a randomized controlled trial. *Lancet HIV*. 2016;3(2):85-93. doi: 10.1016/S2352-3018(15)00247-7.
- 14. Govindasamy D, Meghij J, Negussi EK, Baggaley RC, Ford N. & Kranzer K. Interventions to improve or facilitate linkage to or retention in pre-ART (HIV) care and initiation of ART in low- and middle-income settings--a systematic review. *Journal of the International* AIDS Society. 2014;17(1):19032. doi:http://dx.doi.org/10.7448/IAS.17.1.19032.
- 15. Roy M, Czaicki N, Holmes C, Chavan S, Tsitsi A, Odeny T, et al. Understanding Sustained Retention in HIV/AIDS Care and Treatment: a Synthetic Review', *Current HIV/AIDS Reports*, 2016;13(3):177–185. doi: 10.1007/s11904-016-0317-9.
- 16. American Academy of Paediatrics Committee on Hospital Care. Family Centred Care and the Paediatrician's Role. *Paediatrics*. 2003;112:691-697. <a href="http://dx.doi.org/10.1542/peds.112.3.691">http://dx.doi.org/10.1542/peds.112.3.691</a>.

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17	. Iwelunmor J, Airhihenbuwa CO, O	koror	TA, Brown	DC. an	d Belu	e R. Family	Systems
	and HIV/AIDS in South Africa', I	Int Q	Community	Health	Educ,	2006;27(4):	321–335.
	doi:10.2190/Ig.27.4.D.						

 Charurat M, Oyegunle M, Benjamin R, Habib A, Eze E, Ele P, et al. Patient retention and adherence to antiretrovirals in a large antiretroviral therapy program in Nigeria: A longitudinal analysis for risk factors. *PLoS ONE*. 2010;5(5):10584. doi:10.1371/journal.pone.0010584.

19. Arrive E, Dicko F, Amghar H, Aka AE, Dior H, Bouah B, et al.

HIV Status Disclosure and Retention in Care in HIV-Infected Adolescents on Antiretroviral Therapy (ART) in West Africa. *PLoS ONE*. 2012;7(3):33690. doi:10.1371/journal.pone.0033690.

- Ntanda H, Olupot-Olupot P, Mugyenyi P, Kityo C, Lowes R, Cooper C, et al. Orphanhood predicts delayed access to care in Ugandan children. *Pediatr Infect Dis J*. 2009;28(2):153-5. doi:10.1097/INF.0b013e318184eeeb.
- Tiruneh YM, Galárraga O, Genberg B, & Wilson IB. () 'Retention in Care among HIV-Infected Adults in Ethiopia, 2005–2011: A Mixed-Methods Study', *PLoS ONE*, 2016;11(6):0156619. doi:10.1371/journal.pone.0156619.
- 22. Campbell C, Skovdal M, Mupambirey Z, Madanhire C, Nyamukapa C. & Gregson S. Building adherence-competent communities: factors promoting children's adherence to anti-retroviral HIV/AIDS treatment in rural

Zimbabwe', *Health* & *place*, 2012;18(2):123-131. doi:10.1016/j.healthplace.2011.07.008.

23. Ulrich R, Zimring C, Quan X, Joseph A, & Choudhary R. Role of the Physical Environment in the Hospital of the 21st Century Centre for Health Design. The Centre for Health Design for the Designing the 21st Century Hospital Project. 2004. Available at: https://www.healthdesign.org/sites/default/files/Role%20Physical%20Environ% 20in%20the%2021st%20Century%20Hospital\_0.pdf (Accessed: 30 July 2016).

24. Layer EH, Kennedy CE, Beckham SW, Mbwambo JK, Likindikoki S, Davis WW, et al. Multi-Level Factors Affecting Entry into and Engagement in the HIV Continuum of Care in Iringa, Tanzania. *PLoS ONE*. 2014;9(8):104961. doi:10.1371/journal.pone.0104961.

- 25. Kerry AT, Erastus OC. & Tony R. Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB patients in Kibera, Nairobi, Kenya. *Trop Med Hyg.* 2011;105(6):320-6. doi 10.1016/j.trstmh.2011.02.011.
- 26. Vietnam Authority of HIV/AIDS Control. Enrolment and Retention in HIV Care and Treatment Services in Vietnam: Facilitators and Barriers for People Living with HIV.2012. Available

at:<u>https://www.fhi360.org/sites/default/files/media/documents/Enrolment%20and%</u> 20Retention%20(ENG).pdf (Accessed: 18 August 2016).

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- Coding of transcripts was performed manually
- The data was then charted into thematic matrices and interpreted.

The generated themes were pooled and integrated into common themes based on which the results were organised.<sup>12</sup>

#### **Ethics**

The approval of the research and ethics committee of ABUTH, Zaria was obtained

#### Aim

To explore the enablers to retention in the paediatric HIV clinic of ABUTH, Zaria, Nigeria.

#### Results

The enablers to retention were categorized at the intrapersonal, interpersonal, community, and health care system levels, as shown in Figure 3.

# Demographic profile of participants

# Enablers to clinic attendance

#### Intrapersonal level

Good health-seeking behaviour of the caregivers emerged as an enabler to retention in clinic. Many participants felt that the understanding of the value of the clinic, and the observed improvement in the health of their children were strc..., ating factors.

"The clinic is very important, because ....., once he starts taking the drugs, [....] he will stop falling sick frequently"

Service providers felt that having a biological parent and the grandparents as caregivers is an enabler to clinic attendance as opposed to guardians. They were perceived to be more involved in the care of the child.

"... if they are biologically related to the child like the parents, they tend to be more involved in the care of the child, you will be able to discuss a lot of issues with them [...] ... "

#### **Interpersonal level**

Good family dynamics was perceived to be a facilitator to retention in clinic. In the same vein, support from the family both psychological, material, and even bringing the child to the clinic itself emerged as a strong motivator.

"..., my husband supports me a lot, he is negative, but he will bring us (herself and her child) to the clinic with his car, park his car, and wait for me for as long as I am in the clinic, and afterwards he takes me back home"

#### **Community level**

Support from members of the community emerged as a strong reason for retention in clinic. Many of the participants expanded on this to include support such as aiding the caregivers with money for transport, and supporting children, particularly orphans, with food, clothing and so on.

"Some people in the community use to help with transport money......",

However, the fear of discrimination has hindered the ability of some caregivers to access this support from the members of their community because of stigma.

Disclosure to trusted members of the family and community was similarly perceived to be an enabler to clinic attendance.

"It is good if you have somebody you trust to tell him/her about the status of your child because, in the event that you die before the person, she/he will be able to take care of your child's clinic requirements"

#### Health care system

Locating the clinic away from the main hospital provides privacy, which facilitates clinic attendance. Participants also felt that the cleanliness and spaciousness of the clinic, coupled with air-conditioned consulting rooms, makes attending the clinic comfortable and encourages retention.

"... There is confidentiality... and the rooms are well air conditioned, so the doctor and the patient are all comfortable"

Positive staff attitude to caregivers emerged as a strong motivator for remaining attached to the clinic. This was perceived by the caregivers as kind words, respect, and politely correcting them when they erred.

"What we love when we bring our children is to be shown sympathy..., perhaps the child is an orphan, so when the mother comes, she should be treated kindly, they should not shout at her"

In addition to giving the ARVs free, other incentives such as breast milk substitutes and mosquito nets emerged as major reasons for retention in the clinic.

"In those days when we started newly there were little things they used to give us, things like mosquito net, water guard..., I think it can also encourage attendance at the clinic"

Participants felt that a high standard of care was an important motivator for retention in clinic. Quality was felt to have a range of dimensions, including waiting times, skills and knowledge, availability of support services and a flexible patient-centred approach to care. They cited qualified, professional staff, availability of laboratory services, availability of drugs, and prompt

attention, as reasons for retention. Having integrated services in a clinic and giving the same appointment date for caregivers who are HIV positive and their children were the other enablers that related to the standard of care.

'Some prefer to come here regardless of the distance because the services here are better... in those other places, they will tell you that they have taken your blood to another place for test[ting], but here they do everything and you see your result'

The presence of a peer support group in the clinic for the caregivers was perceived as an enabler for clinic retention. Many participants elaborated on this citing the benefits of the support group such as psychological support, helping to combat stigma, material gains, and finding marital partners.

"The support group provides them with the opportunity to interact with one another, learn vocational skills; some have met new partners, and some have even been employed in the clinic

here"

Proactive tracking of defaulters by clinic staff was seen as an important reason for retention.

"It will help if those that have stopped coming are followed to their homes and counselled, they will understand, return and continue to take their drugs"

Interestingly, false notions surrounding the continuity of free ARVs have made some caregivers regular with their clinic attendance. This was out of the fear that, very soon the drugs will cease to be free and they will have to be buying.

"I heard that American people say they will stop giving drugs, so I don't want to stop coming to clinic so that the little I have will sustained me before I [have to] start buying when they stop [being free]

### Discussion

Incentives given at the clinic such as transport money and food emerged as a strong enabler to retention. This is consistent with the finding from Kinshasa in the Democratic Republic of Congo, where conditional cash transfers increased retention in clinic within the PMTCT programme by 7.8 %.<sup>13</sup> This has also been corroborated in a systematic review on improving linkage and retention in HIV care.<sup>14</sup>

Good relationship between a caregiver and her/his spouse was found to be an important reason for retention in clinic. This echoes the finding from the latest qualitative synthetic review on the reasons for retention in SSA. The review showed that a good relationship between a couple leads to social normalization with the HIV situation and improved clinic retention.<sup>15</sup>

The larger family support, including support from siblings, was found to be important in ensuring retention to care. This agrees with the American Academy of Paediatrician's definition of the family as the primary source of strength and support for the child.<sup>16</sup> It is also consistent with a study in South Africa.<sup>17</sup> It was therefore not surprising that disclosure of the status of the child to close family members and a trusted few in the community was found to be an important enabler to retention in care. This was similarly reported from five HIV care centres across Nigeria<sup>18</sup>, and from across the West African sub-region.<sup>19</sup>

Parent and grandparent caregivers were associated with better retention. this could be related to the fact that the orphans have the added vulnerability of missing parental support. Studies have shown the retention of HIV-infected orphans to be worse than that of the children whose parents are still alive.<sup>20</sup>

Support from the wider members of the community was found to be an important enabler to retention, consistent with the findings from Ethiopia<sup>21</sup> and Zimbabwe.<sup>22</sup> Nonetheless, the availability of the support to the caregivers was limited by perceived stigma in the community. This is consistent with the findings from Ethiopia.<sup>21</sup>

The study found that a clean, spacious, well-ventilated clinic, with recreational facilities was a reason for retention in the clinic, as substantiated in the literature.<sup>23</sup> Friendly staff attitude to caregivers was found to be a strong facilitator to retention as was found in Tanzania.<sup>24</sup>

Tracking of defaulter's increases retention partly because it encourages re-engagement, and because some clients prefer to come to the clinic to avoid being traced via home visits for fear of disclosure of their status. This agrees with the study in Kenya.<sup>25</sup> The study additionally found that the caregiver support group in the hospital was a reason for retention, as was also found in Vietnam.<sup>26</sup>

### **Conclusion and Recommendations**

1. Quality improvement initiatives in the clinic should ensure a periodic and systematic capture of caregiver and patient perspectives on quality.

2. The clinic managers could consider introducing incentives such as transport fares generally, and specifically identifying and assisting the orphans.

### References

- 1. World Health Organization. *Global update on HIV treatment 2013*. Available at: http://www.who.int/hiv.pub,mtct/strategic\_vision.pdf. (Accessed: 20 May 2015).
- 2. Bangsberg DR, Kroetz DL & Deeks SG. Adherence-resistance relationships to combination HIV antiretroviral therapy. *Curr HIV/AIDS Rep.* 2007;4(2):65–72.
- 3. Rawizza HE, Chang CA, Chaplin B, Ahmed IA, Meloni TO, Banigbe B, et al. LosstoFollow-Up within the Prevention of Mother-to-Child Transmission Care Cascade in a Large ART Programme in Nigeria. *Current HIV Research*. 2015;13(3):201-209.
- 4. Wettstein C, Mugglin C, Egger M, Blaser N, Vizcaya LS, Estill J, et al. Missed opportunities to prevent mother-to-child-transmission: a systematic review and metaanalysis', *AIDS*, 2012;26(18):2361–2373. doi:10.1097/QAD.0b013e328359ab0c.
- Gerver S, Chadborn T, Ibrahim F, Vatsa B, Valerie C, Delpech VC et al. HIV-Positive Patient Retention in the UK: High Rate of Loss to Clinical Follow-Up among Patients from a London Clinic. *Journal of the International AIDS Society*. 2010; 13:29. doi: 10.1186/1758-2652-13-29.
- Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC & Giordano. Examining the Link between Patient Satisfaction and Adherence to HIV Care: A Structural Equation Model. *PLoS ONE*. 2013;8(1):54729. doi:10.1371/journal.pone.0054729.
- Green J. & Thorogood N. *Qualitative methods for heath research*. London: Sage Publications. 2013. Available At:https://uk.sagepub.com/engb/eur/qualitativemethods-for-health-research/book239018#contents. (Accessed: 8 July 2016).

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- 8. McLeroy KR, Bibeau D, Steckler A. & Glanz K. An ecological perspective on health promotion programs. *Health Education Quarterly*. 1988;15(4):351-377.
- National Population Commission Abuja. Legal Notice and Publication of Details of the Breakdown of the National and State Provisional Totals of 2006 Census Federal Government of Nigeria Official Gazette: No. 24 Vol. 94. Available At: http://allafrica.com/stories/200705241002.html (Accessed: 10 June 2016).
- 10. Umar LW, Musa S, Abdullahi FL, et al. Trends in Loss-to-follow-up at a Tertiary Paediatric HIV Treatment Centre in Northern Nigeria. *Presented at the Joint UNAPSA/PAN International Conference, Abuja, Nigeria, January 2018.*
- 11. Kurtz S, Silverman J, Benson J, Draper J. Marrying Content and Process in Clinical Method Teaching: Enhancing the Calgary-Cambridge Guides. *Acad Med*, 2003;78(8):802-9.
- Ritchie J, Spencer L. & O'Connor W. (b). 'Carrying out Qualitative Analysis. In: Ritchie, J. & Lewis, J. (eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Wiltshire, UK: SAGE Publications, 2003:219262.
- Yotebieng M, Thirumuthy H, Moracco KE, Edmonds A, Tabala M, Kawande B, et al. Conditional cash transfer to increase retention in PMTCT care, antiretroviral adherence, and postpartum virological suppression: a randomized controlled trial. *Lancet HIV*. 2016;3(2):85-93. doi: 10.1016/S2352-3018(15)00247-7.
- 14. Govindasamy D, Meghij J, Negussi EK, Baggaley RC, Ford N. & Kranzer K. Interventions to improve or facilitate linkage to or retention in pre-ART (HIV) care and initiation of ART in low- and middle-income settings--a systematic review. *Journal of the International* AIDS Society. 2014;17(1):19032. doi:http://dx.doi.org/10.7448/IAS.17.1.19032.
- Roy M, Czaicki N, Holmes C, Chavan S, Tsitsi A, Odeny T, et al. Understanding Sustained Retention in HIV/AIDS Care and Treatment: a Synthetic Review', *Current HIV/AIDS Reports*, 2016;13(3):177–185. doi: 10.1007/s11904-016-0317-9.
- 16. American Academy of Paediatrics Committee on Hospital Care. Family Centred Care and the Paediatrician's Role. *Paediatrics*. 2003;112:691-697. http://dx.doi.org/10.1542/peds.112.3.691.

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17. Iwelunmor J, Airhihenbuwa CO, Okoror TA, Brown DC. and Belue R. Family Systems and HIV/AIDS in South Africa', *Int Q Community Health Educ*, 2006;27(4):321–335. doi:10.2190/Iq.27.4.D.

 Charurat M, Oyegunle M, Benjamin R, Habib A, Eze E, Ele P, et al. Patient retention and adherence to antiretrovirals in a large antiretroviral therapy program in Nigeria: A longitudinal analysis for risk factors. *PLoS ONE*. 2010;5(5):10584. doi:10.1371/journal.pone.0010584.

19. Arrive E, Dicko F, Amghar H, Aka AE, Dior H, Bouah B, et al.

HIV Status Disclosure and Retention in Care in HIV-Infected Adolescents on Antiretroviral Therapy (ART) in West Africa. *PLoS ONE*. 2012;7(3):33690. doi:10.1371/journal.pone.0033690.

- Ntanda H, Olupot-Olupot P, Mugyenyi P, Kityo C, Lowes R, Cooper C, et al. Orphanhood predicts delayed access to care in Ugandan children. *Pediatr Infect Dis J*. 2009;28(2):153-5. doi:10.1097/INF.0b013e318184eeeb.
- Tiruneh YM, Galárraga O, Genberg B, & Wilson IB. () 'Retention in Care among HIV-Infected Adults in Ethiopia, 2005–2011: A Mixed-Methods Study', *PLoS ONE*, 2016;11(6):0156619. doi:10.1371/journal.pone.0156619.
- 22. Campbell C, Skovdal M, Mupambirey Z, Madanhire C, Nyamukapa C. & Gregson S. Building adherence-competent communities: factors promoting children's adherence to anti-retroviral HIV/AIDS treatment in rural Zimbabwe', *Health & place*, 2012;18(2):123-131. doi:10.1016/j.healthplace.2011.07.008.
- 23. Ulrich R, Zimring C, Quan X, Joseph A, & Choudhary R. Role of the Physical Environment in the Hospital of the 21st Century Centre for Health Design. The Centre for Health Design for the Designing the 21st Century Hospital Project. 2004. Available at: https://www.healthdesign.org/sites/default/files/Role%20Physical%20Environ% 20in%20the%2021st%20Century%20Hospital\_0.pdf (Accessed: 30 July 2016).
- 24. Layer EH, Kennedy CE, Beckham SW, Mbwambo JK, Likindikoki S, Davis WW, et al. Multi-Level Factors Affecting Entry into and Engagement in the HIV Continuum of Care in Iringa, Tanzania. *PLoS ONE*. 2014;9(8):104961. doi:10.1371/journal.pone.0104961.
- 25. Kerry AT, Erastus OC. & Tony R. Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and

TB patients in Kibera, Nairobi, Kenya. *Trop Med Hyg.* 2011;105(6):320-6. doi 10.1016/j.trstmh.2011.02.011.

26. Vietnam Authority of HIV/AIDS Control. Enrolment and Retention in HIV Care and Treatment Services in Vietnam: Facilitators and Barriers for People Living with HIV. 2012. Available

at:<u>https://www.fhi360.org/sites/default/files/media/documents/Enrolment%20and%</u> 20Retention%20(ENG).pdf (Accessed: 18 August 2016).

to per period





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Figure 2: Structure of the themes underlying retention in clinic

Perez

Characteristic	No.	%
Age bracket		
<30	2	11.1
30-40	7	38.9
41-50	6	33.3
51-60	3	16.7
Sex		
Male	4	22.2
Female	14	77.8
Education		
Informal	4	22.2
Primary	6	33.3
Secondary	4	22.2
University	1	11.1
Diploma	3	16.7
Relationship to child		
Father	4	22.2
Mother	11	44.5
Aunt	1	5.6
Grandmother	1	5.6
Self	1	5.6

Table 2: Demographic profile of caregivers

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Table II: Characteristics of Service providers

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8	Characteristic		Number	Percentage (%)
9	Sex	Male	7	41
10		Female	10	59
11	Cadre	Consultants	2	12
12	Cault	Pagidanta	2	12
13		Residents	2	12
14		Nurses	4	22
15		Trackers	1	6
10		Record staff	2	12
18		Administrator	1	6
19		Pharmacist	1	6
20		Dete mene ser	1	6
21		Data manager	1	0
22		Cleaner	1	6
23		Security	1	6
24		Support worker	1	6
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