

## Barriers to Retention in HIV Infected Children on ART: Improvement Strategies at Kaduna State Comprehensive Health Care Facilities in Nigeria

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#### Abstract

**Objectives:** Identified factors that contributed to poor retention in care of HIV infected children initiated on Anti-Retroviral Treatment and recommended appropriate improvement strategies.

Study design: A total of 134 individuals were selected using purposive sampling and participated in the Focused Groups Discussions (FGDs), drawn from Caregivers support groups, HIV positive adolescents and health care workers at the ART clinics.

**Methods:** Exploratory qualitative method using FGD questionnaire guide and retrospective review of secondary cohort clinical data records covering a period of 12 months was conducted using standardized data abstraction forms.

**Results:** There were few studies that had been conducted in Nigeria to explore enablers of retention in care of HIV positive children. However, similar studies from other settings exited. Barriers to retention in care were the most commonly reported across the FGDs, though enablers were also reported. There was also a significant correlation between participant's responses and data analyzed from the hospital records.

**Conclusion:** It was mostly barriers to retention in care that were reported. Some barriers, however, were reported as enablers to retention in care. Caregiver's role is critical and additional integrated strategies are urgently required to achieve optimum retention in care of children.

*Keywords: Retention in care; HIV positive children, Barriers to retention, Enablers to retention, Loss to follow up, Caregivers.* 

## Introduction

HIV/AIDS remains one of the major health challenges facing Nigeria (PEPFAR, 2012). The adult and child HIV prevalence are estimated at 3.1% and 4.4, respectively (UNICEF, 2006). About 60,000 Nigerian children were infected with the virus in 2012, the highest in the world (Premium times, 2013). In the absence of accurate statistical data on children not retained in care and treatment, it is estimated that, 40% are recorded as loss to follow up each year across the comprehensive health care facilities in Nigeria (Nigeria HIV/AIDS National Guidelines, 2010). Benue state in Nigeria has a population of 4.253.641 million people, with HIV prevalence of 5.7% (NACA, 2015). The Federal Government, State Government and donor community has over the last 10 years invested in interventions and strategies to increase ART access to HIV infected persons in order to improve quality of life (Oladele, 2018) President's emergency Program for AIDS Relief (PEPFAR) has supported both national and international HIV implementing organization to provide free ARVs and related services to adults infected with HIV and children with the aim of reducing HIV-related morbidity and mortality (PEPFAR, 2014). The identification of factors responsible for poor retention in care of children is of paramount importance to develop interventions that will improve their optimal health outcomes (PEPFAR, 2014). Optimal retention in care of children may be associated with similar factors as in adults but will in addition depend on the caregiver (Mugglin, Catrina, and Wanderer 2013). Despite the availability of free ARVs and sizeable number of adult's in-patients and children initiated on ART in Nigeria, Benue state faces the challenge of poor retention in care of HIV positive patients. The aim of this study was to examine the barriers that has led to poor retention of HIV infected children in



paediatric care and treatment at Kaduna state, Nigeria, and the facilitating factors for improvement in retention in care and treatment.

Retention in care and treatment of HIV positive children is critical to their survival (De Schacht C, 2014). Efforts to address barriers to retention in care, loss to follow up of children initiated on treatment remains high (Mugglin C, 2013). In Nigeria, pediatric retention in care is 7% compared to 26% in adults (WHO, 2011). This study contributes to an understanding of the barriers militate retention in care of HIV infected children. The significance of this work helps in designing strategies for improved retention in care and treatment, and this will enhance child survival, through HIV viral control and access to ancillary services (Geng EH, 2010). Furthermore, improved retention in care will provide benefits that help infected children live a quality, long life (WHO, 2012). Through a comprehensive assessment of the ART, clinical attendance and services data, group discussion feedback, valuable knowledge will be gained on factors causing the barriers, leading to design of strategies to improve retention in care for HIV infected children.

This research is innovative as it addresses the causes of poor retention in care and treatment for HIV/AIDS, focusing on children rather than the adults as indicated by several research. Several research reports have concentrated on adult's groups with an assumption that similar conditions apply in children (WHO, 2012). Adults and children are completely different in their attitudes towards medication and normally pediatric treatment demands parenthood, proper facilities, human resource for child care and ART that are not necessarily like that of adults (UNICEF, 2014). The research comprehensively assesses the barriers to poor retention in child HIV care and treatment and will impact on HIV infected children by improving quality of life through continuous access to the HIV/AIDS care (Dalhatu 1, 2016). The study contributes immensely towards public health field and other allied professionals, clinical care of patients that required lifetime medication provide recommendations that will inform further research on improved children's retention in care and treatment of HIV/AIDS.

To investigate the barriers of retention in HIV infected children, a literature search for similar studies was conducted in Nigeria and from other limited resource settings. Study participants included caregivers of HIV positive children, Caregivers support groups, HIV positive adolescents and health care workers at the comprehensive ART clinics. The study was designed to answer questions whether poor retention in care of children that are HIV positive a result of factors; lack of money, stigma and discrimination, long distances to health facilities and others and if also long waiting time, poor patient/health care work relation, poor attitude stigmatization, prevents caregivers from returning their children at the health facilities for continued care and treatment support.

## Methods

## Study site

This study was undertaken at four comprehensive health care facilities; General Hospital Gwantu, Baraudiko Teaching Hospital, General Hospital Kachia and General Hospital Kafanchan. These are mainly referral hospitals with ART clinics General Hospital Gwantu, Kafanchan and Kachia are in Southern Kaduna, while Baraudiko teaching Hospital is in northern part of Kaduna state. The Four facilities are in the urban or peri- urban parts of the states and are part the group of hospitals supported by the Nigeria's federal Government and Kaduna state. The study sites were selected because they are high volume hospitals supported by the Government to provide comprehensive care, support and treatment services for People living with HIV/AIDS (Fig 1). Kafanchan hospital has enrolled 8,923 adult PLHIV and 3,240 children in care and ART treatment while Baraudiko has enrolled 14,992, adults and 2,902 children respectively (NACA, 2016). In addition to the adult ART clinic, each hospital has an established HIV/AIDS paediatric clinic that offers ART services for young children (Awofala A, A 2016). Each hospital is attached with an adult support group of People Living with HIV/AIDS where new patients are enrolled for peer psychosocial support. After 6 months, the patients are discharged to the community-based support groups. Kafanchan support group is one of the community-based support where this study was also undertaken. The table below indicates the 4 study sites marked with double asterisk.

#### **Study setting limitations**

The appropriate sites for this was the high-volume HIV/AIDS treatment sites, obtaining permission for to use the sites took time hence commencement of the study did not commence on time as per scheduled time lime in the study work plan. Identifying willing caregiver's who reside near the study sites as a way of reducing transport costs to attend FGD meetings was not feasible. Study sites with highest volume paediatric HIV positive children declined to give consent for record review while those that accepted only limited the review to aggregate data, hence vital and detailed data to track trends in retention was cumbersome. The process for seeking permission from study sites administrators was tedious, time consuming and bureaucratic as it involved various levels of approval. There was multiple postponement of discussion appointment dates particularly health care workers FGD group since same proposed dates conflicted with their work schedules.

#### Study design

The study was carried out between June 2016 and August 2017 through exploratory qualitative method. In order to reach data saturation, participants in FGD were selected using purposive sampling from targeted population categories; caregivers/parents (n=16) enrolled in community based adult PLHIV support groups linked to each Health facility, older HIV positive children (15 to 18) year of age (n=12) enrolled at paediatric ART clinics, and ART clinic health care workers at each of the hospitals (n=15). Each FGD met once and open-ended questions were developed on interview questionnaires to guide the discussions. Each group was facilitated by a neutral group moderator (facilitator). Health care workers who participated in the study were given permission and approval from the hospital administrative authorities. Focal persons of PLHIV support groups assisted in contacting participants (caregivers/parents) while the in charge of paediatric ART clinics contacted the healthcare workers. Trained research assistants were identified to assist in conducting the study and to assist FGD facilitators during FDG meetings.

The study also involved retrospective review of secondary cohort clinical data records from ART clinics at each of the health facilities (study sites) covering a period of 12 months in 2016. Data was extracted from pre-enrolment ART, defaulters, tracking and loss to follow up registers from data already recorded and summarized. The study on barriers to retention in care and treatment of HIV/AIDS focused on caregivers of children infected with HIV/AIDS who were enrolled and were still active in care covering the study period. An active care giver in care was defined as individuals seen in the facility at every hospital appoint during a prior specified period by the clinicians at the treatment site (Holmes J, 2018).

#### **Study design limitations**

Focus Groups Discussions involve small sample size, so this may not provide effective representation of the views or responses of the larger intended study population. Conducting FGDs in the health care facilities caused some uneasiness amongst caregivers with stable children on ART since their frequency to the facilities was limited by that time. Participants in the FGDs were from multiple ethnic and sub tribal groups, hence interpreters might have missed or mixed up responses in a language they were not conversant with, leading to in accurate interpretation of the responses. Skills of the moderators could have affected responses and the results and time was lost on topics that were not relevant to study. Participants included only caregivers of HIV positive children, possible inclusion of PABAs could have enriched the responses. Other PLHIV participants may have had different or additional views on barriers to retention in care of positive children.

#### Sampling procedures

The targeted population for sampling procedures were both men and women that were caregivers of HIV positive children initiated on ART, HIV positive older adolescent girls and boys and health care workers both male and female working at the HIV/AIDS comprehensive treatment sites. A list of participants that were purposively selected was drawn and research assistant contacted each member of the sample (Stephanie P, 2015).

The exploratory qualitative method was used to carry out the study. Participants in FGD were selected using purposive sampling from targeted population categories; caregivers/parents (n=16) enrolled in community-based adult PLHIV support groups linked to each Health facility, older HIV positive children (15 to 18) year of age (n=12) enrolled at pediatric ART clinics, and ART clinic health care workers at each of the hospitals (n=15). Both critical case and maximum variation sampling methods were applied to collect cases that were likely to give the most information about the barriers to retention in care and to have access to a wide range of participants with different viewpoints on retention in care for HIV/Positive children. The advantage of this sampling procedures was that it makes it easier to generalize about sample selected participants compared to others like random sampling where not all participants have the characteristic that was being studied. The down side of this procedure is about the openness to selection bias error. Each FGD met once and open-ended questions were developed on interview questionnaires to guide the discussions (Holmes, 2015). All participants in the FGD signed the informed consent form. Responses from each of FGDs were audio-recorded, transcribed, and coded. Data was collected by research assistants with the help of some PLHIV (participants) and some health care workers. Data from the FGD was analyzed using Krueger's (1994) framework analysis by Ritchie and Spencer.

## **Study population**

The target study population for this study were children who are HIV positive that enrolled in care and were on ART. To get a broad perspective of the barriers to retention in care of children infected with HIV/AIDS, three categories of participants were included in the study; caregivers or parents of HIV positive children, initiated on paediatric ART, Older HIV positive children (> 15 but below 18 years) on paediatric ART and health care workers at the ART clinics. Participants from among caregivers or parents were those enrolled as support group members and were selected regardless of their sex, age, location or education. Older children who participated in the study were adolescent girls and boys in the age range of (15-18) years. The targeted health care workers were nurses, data clerks, adherence counsellors and medical officers working in the ART clinics.

#### **Study participants limitations**

Earlier participants declined to participate in the study due to unpleasant experiences where earlier researchers breached HIV/AIDS status confidentiality of selected or willing study participants. Extra resources had to be expended on organizing repeated pre-study participation orientation seminars to create in depth awareness about the study sensitize and building confidence for their maximum confidentiality and commitment for zero breach through signing and explaining content in the consent forms. FGD time table was altered frequently accommodate time for availability of FGD selected participants particularly that it was a rainy season and hence, prioritized their farming activities.

#### Data collection and analysis

Data was generated from FGDs by recording interview responses and from the observational notes that were immediately typed by FGD moderators' group. Data was analyzed using interpretative phenomenology analysis. FGD moderators listened to the recorded tapes, transcribed the information and read it over (Watson S A, 2016). This process helped in getting the general overview of responses from each group to emerge. Data on caregivers and children initiated on ART for a period of twelve months (Jan 2016-December 2016) was abstracted from the medical records with the help of record clerks at each study site using data abstraction sheets. Data source documents were the hard copies of Pre-enrolment ART Log book, Pediatrics ART Log.

#### **Data sources**

The literature under review was sourced both from primary and secondary data sources. Primary data was collected from registers at comprehensive health facilities, audio recorded FGD responses and from FG transcribed manuscripts. Secondary data was obtained from peer reviewed articles, reports in academic journals, publications and text books. The Literature search was conducted through PubMed (MEDLINE database), home scholarly academic libraries and Medical record records databases at the

Health care facilities. Cumulative data for the period under study was extracted from pre-enrolment ART, defaulters, tracking and loss to follow up registers, from data already recorded and summarized. The study on barriers to retention in care and treatment of HIV/AIDS focused on caregivers of children infected with HIV/AIDS who were enrolled at the facilities covering the study period. Permission from hospital authorities to access patient's data was limited only to aggregated numbers in the registers and log books because it was not possible to get consent to review medical records on HIV pediatrics due to ethical issues related to medical record reviews (Levine C A, 2017).

#### Data collection and analysis from primary and secondary data sources

#### Procedures

Key items for data extraction were specified in advance in a data extraction template, based on the participants, interventions, comparisons key outcomes from the study. A standardized data extraction sheet was used to extract inclusion criteria that included key themes; characteristics of the program, setting, location, country, characteristics of the children; age, sex and HIV status, definition of LFU and defaulter tracking" (Noyes & Lewin, 2011). Findings of the studies were presented in text, tables, mapping and diagrammatic representations forms.

# Data collection and analysis from hospital pediatrics medical Records-Primary data source

#### Procedures

The study also involved retrospective review of secondary cohort clinical data records from ART clinics at each of the health facilities covering a period of 12 months in 2016. A patient in the paediatric register was defined as children with a known reactive HIV status and initiated on ART in the age arrange of (1-18years). Summary of numbers from each activity was extracted from pre-enrolment ART, defaulters, tracking and loss to follow up registers from data already recorded and summarised. Data collection was carried out using a standardized data abstraction form administered at the HIV medical records section of the hospital. Data from each register was recorded in a designed data collection sheet and this was useful in checking consistency and validity of data. The most reliable source of data was picked form registers and log books because of ease of access and summaries that are collected per month and recorded at each month end page. Reviewing of data in the registers was done with the assistance of data entry clerks and all listed registers for review were pulled from the filing cabinets, tagged with temporarily stickers in order of the subject for which data was to be reviewed. All registers pertaining to the subject of review were retrieved and searched for the required data. The study on barriers to retention in care and treatment of HIV/AIDS focused on caregivers of children infected with HIV/AIDS who were enrolled at the facilities covering the study period. The study received ethical approval from each of the four study sites. See copy of the letter of permission that is attached in appendix section. At this point no informed consent was required from study participants. The diagram below indicates the process for retrieving data from medical records of HIV positive children at the selected study sites.

## Results

A total of 140 participants were purposively selected and met the section criteria for participating in the study. All selected participants were contacted on this selection out of which 134 returned acknowledgment for acceptance to participate in the FGDs. This included: Adult PLHIV (n-16), who are parents to children that are HIV positive, Older HIV/AIDS positive children 15-18 years (n-58) old and ART clinic Health care workers (n-60). All participants fully attended and participated in the FGD for the stipulated period. Two pre-designed questionnaires were used; one was designed in the local Language (Hausa) for the FDG that comprised care givers while FGD for the remaining category of participants were guided by a questionnaire written in the English language. The barriers to retention in care were divided into two types: Social and economic barriers that were either physical or structural in nature. A copy of the FGD questionnaire and facilitators questionnaire guide is attached in the appendix section.

There was uniformity in views and responses across the FGDs except for health care workers and adolescents FGD. For example, responses from health caseworkers FGDs did not agree to the poor patient-health care worker relationship though some of them agreed that individual health care workers exhibited negative attitudes to caregivers because of their HIV status and their children. What most health workers emphasized in their responses was that poor motivation particularly delayed salary payments affected their moral to work. This could be a driver for aggressiveness and rudeness among the staffs. Some adolescents did not see the long distances or high transport costs as barrier to retention in care because most of them are still dependents with full support from their caregivers or parents.

The study also involved retrospective review of secondary cohort clinical data records from ART clinics at each of the health facilities covering a period of 12 months in 2016. A patient in the paediatric register was defined as children with a known reactive HIV status and initiated on ART in the age arrange of (1-18years). Summary of numbers from each activity was extracted from pre-enrolment ART, defaulters, tracking and loss to follow up registers from data already recorded and summarised. Data that was need and extracted was for a period of twelve months (Jan 2016-December 2016). Data extractions was done with the help of record clerks at each study site. Data source documents were the hard copies of Pre-enrolment ART Log book, Paediatric ART Log book, Defaulter trackers log book and loss to follow log books where total number of adult PLIHIV that received services were summarised. Graphs were used to analyse trends on children who defaulted treatment and those who were tracked and returned in care for a period of one year (January 2016- December 2016). This also included analysis of loss to follow up children. Data from each register was grouped into data categories and placed in tables as shown below:

## Discussions

Barriers to retention in care of HIV positive children were the most commonly reported across the FGDs, though enablers to retention in care were also reported. There is a significant correlation between participant's responses and data analysed from the hospital records. The literature review of the included studies provided comprehensive information that was relevant to this study. The studies explored indepth the barriers and enablers that promote or discourage retention in care of HIV positive children. The resources that should enable retention of children in care were mainly reported by all FGD participants including health care workers who participated in this study. Whereas the literature reviews provided substantial information, findings of this study give a deeper insight on barriers and enablers that can either encourage or discourage retention in care of HIV positive children.

Although literature on retention in care of HIV positive children is limited, there exists other sources such as medical records and registers that could provide valuable primary data sources on barriers to retention in care. There are few studies that have been conducted in Nigeria to explore enablers of retention in care of HIV positive children as a means of assessing poor retention outcomes. However, similar studies from other settings exits on this subject. It is recommended that more literature from those settings is accessed and reviewed to provide scenarios, strategies, interventions and best practices that can be adopted in addressing the problem of poor retention in care of HIV positive children in Nigeria. A few reports and articles with results that support and speaks to the study questions of this research were identified. The CDC, 2018 presentation on interventions for poor retention in care of children infected with HIV was a valuable resource that will be used as a reference material while conducting further studies on the recommendations, interventions, strategies and outcomes of this study.

#### Barriers to retention in care

Barriers to retention in care of HIV positive children were the most commonly reported across the FGDs, though enablers to retention in care were also reported. There is also a significant correlation between participant's responses and data analyzed from the hospital records. The literature review that was conducted provided comprehensive information, however this study explores in-depth the barriers and enablers that promote or discourage retention in care of HIV positive children. There was uniformity in the views and responses across the FGDs except for health care workers and adolescents. Responses from most of the health caseworkers FGDs did not agree to the poor patient-health care worker relationship although some participants acknowledged that some individuals have been pointed

out by caregivers for maltreating them at the ART clinic. Poor and delayed pay of remunerations was cited by health care workers at one of the health facilities as demotivation factor affecting their moral at work that drives poor patient relationship. Recent studies have been conducted on attitude of health care workers towards patients and measure outcomes indicate poor patience/health care worker relations (Ledda C, 2017). Poor working conditions, lack of adequate equipment and poor and delayed remunerations are drivers of poor attitudes. Parents have discontinued from health facilities due to abuses inflicted on them, rudeness and abusive languages of health caseworkers (Lifson, Demissie, and Tadesse, 2016). Therefore, hospital administrators and Government need to urgently address issues affecting motivation of health care workers by providing incentives through improved working conditions, access to equitable capacity building programs, promotions at work and better pay. Training and retraining of health care workers on soft skills such as effective communications skills and customer care relationship skills are extremely critical in addressing this challenge.

Some adolescents did not see the long distance or high transport costs as barrier to retention in care because most of them are still dependants with full support of their caregivers or parents. In this study, barriers and facilitators to retention in care are reported from across the four FGD and will inform interventions that can mitigate barriers to retention in care of HIV positive children. Some of the reported resources could be both barriers and enablers depending on the context and environment (Berth, Naanyu, and Wachira, 2016). Accessibility to health facilities can be both a barrier and an enabler to retention depending on the location and distance between the caregiver's home and health facility. This is influenced by factors such as a lack of money for caregivers in long distances away from the facilities that are far away from their homes due to stigma, this can lead to increased transport costs. Though nearness to health facilities reduces transport costs and improves retention, there are other structural challenges that must be addressed by services providers as part of a comprehensive and intergraded strategic planning for improving retention in care.

#### **Enablers to retention in care**

The resource drivers that should enable retention of children in care were mainly reported by FGD participants as the barriers to retention in care of HIV positive children. Whereas the literature reviews provided substantial information, findings of this study give a deeper insight on barriers and enablers that can either encourage or discourage retention in care of HIV positive children. A study conducted by (NACA, 2016) showed that clinicians had a more positive patient relationship and therefore that trust enhanced adherence to ARV. In this study, it was found that parents trust in clinicians is further strengthened by the satisfaction of the professional manner and knowledge exhibited during diagnosis and treatment. The likely motivational factors for the patient trust should be extended across all band of health caseworkers to remove attitude barriers.

Accessibility to health facilities was reported as an enabler due to the short distance to the facilities depending on the location and distance between the caregiver's home and health facility. Caregivers who stay close to health facilities may choose to enrol in far health their children in facilities where they are not known due stigma, this can lead to increased transport costs. Though nearness to health facilities reduces transport costs and improves retention, there are other challenges that must be addressed by services providers in during their strategic planning. Availability of drugs was identified and as a stronger enabler, as most participants who regularly attending clinics reported access and availability of ARVs for their children. Donor support has supported the health facilities; hence stock outs are minimal except in circumstances of crisis and workers strikes (AFH, 2018). Peer support was reported as enabler by participants across the groups. Facility and community-based support group's enables sharing of experiences on children treatment and adherence especially for parents with newly HIV diagnosed children.

In addressing the barriers to retention in care, introduction of models of care like differentiated care for HIV positive children could be an important strategy where mothers of stable children are clustered in their support groups within their communities and reached with drug supplies for their children for a period of 3-6 months (FHI 360, 2017). This one way in which stigmatisation at the health facilities will be avoided. Integrating House Hold Economic strengthening and income generating programmes in the

care and support packages is as strategy retention in care. Caregivers can be grouped in savings groups and loaned seed funds that can be accesses on a rotational fund within their group for borrowing to engage in IGAs. Savings groups can be used as paediatric ART pick up clusters for mothers of HIV positive children and a forum for continuous adherence counselling support.

#### Patient/provider relationship

Patient provider relationship can be a barrier but also an enabler to retention depending on the individual personality or motivational hygiene factors of the health care workers. Recent studies have been conducted on attitude of health care workers towards patients. Poor working conditions, lack of adequate equip and poor and delayed remunerations are drivers of poor attitudes. Parents have discontinued from health facilities due to abuse, rudeness and abusive languages of health caseworkers (Lifson A, 2016). Patient provider relationship can be a barrier but also an enabler to retention depending on the individual personality and relationship with the care givers or patient motivational hygiene exhibited by the health care workers. Government response in providing incentives and motivating health workers through improved working condition is critical to caregiver's in keeping caregivers returning to hospital to seek services for their children. Training and retraining of health care workers on soft skills such communications skills and customer care skills are necessary in addressing this challenge. A study conducted by (NACA, 2016) showed that clinicians had a more positive patient relationship and therefore that trust enhanced adherence to ARV. In this study, it is found that parents trust in clinicians is further strengthened by the satisfaction of the professional manner and knowledge exhibited during diagnosis and treatment. The likely motivational factors for the patient trust should be extended across all band of health caseworkers to remove attitude barriers.

#### **Defaulter tracking challenges**

Health care workers who participated in the study expressed concern about the lack of proper support for tracking caregivers who default hospital appointments. The notable system used to track defaulting care giver is through phone calls. The challenges experienced by peer health educators in making calls to track defaulters include; wrong numbers provided by the caregiver's due stigmatisation of their children's HIV status. Phone Network work challenges particularly for care givers living in remote rural areas. Not all caregivers can afford mobile phone sets because they do not have enough money to buy, some depend on their neighbour's phone and only if they are there peers. Lack of electricity in the remote villages makes it impossible for the phone batteries to be charge, hence they will be unreachable when reaching out to them using phone. Despite some of these challenges it is noted the poor motivation of health care workers was due to poor and delayed pay which eroded their commitment to that effect. It no interesting to note that stipends meant to be used by peer educators to make callers and reach out to defaulting caregivers are diverted to meet their needs since their pay is not for the coming. One of the participants in the caregivers FGD suggested peer to peer tracking support model where senior PLHIV care givers support in tracking adolescent's mothers.

## **Study limitations**

Implementation of pilot study at Kafanchan General Hospital delayed because approval from hospital administrators was delayed for 4 months. Permission to review registers and other data capturing tools was only limited to picking summary numbers (aggregate totals) per register hence validation of those numbers was not possible. Participants in the FGDs were from multiple ethnic and sub tribal groups, hence interpreters might have missed or mixed up responses in a language they were not conversant with, leading to in accurate interpretation of the responses. Skills of the moderators could have affected responses and the results and time was lost on topics that were not relevant to study. The small sample size that characterises Focus Groups discussions may not be an effective representation of the wider study population. Other barriers or enablers may not have been captured due peer influence in the groups to give similar responses. The FGD setting and skills of the moderators can affect responses and the results and time can be lost on topics that are not relevant to study. In this study, participants included only caregivers of HIV positive children. Other PLHIV participants may have different or additional views on barriers to retention in care of positive children.

## Conclusion

This study was conducted for a period of one year from June 2016 and August 2017 across the 4 selected comprehensive HIV/AIDS facilities with data collected from a sample size of 134 FGD participants. The barriers to retention in care were divided into two types: Social economic and structural barriers. There was a significant correlation between participant's responses and data analysed from the hospital records on retention. Mostly, it is the barriers to retention that were reported, and most were common to long waiting time, long distances from the health facilities and poor attitude of healthcare workers at the health facilities. Some barriers were also reported as enablers to retention in care and were reported. Barriers also cut across predisposing factors such as drug side effects, shortage or even absence of ARVs at the clinics, continued stigma, cultural belies, farming seasons and insecurity due communal conflicts and insurgency. Poor attitude of health care workers was cited as particularly exhibited by female nurses and counsellors was reported as barrier across all the facilities. Generally, there were few factors mentioned that enable retention in care of HIV positive children compared to the barriers. Interventions that target retention in care among adolescents living with HIV are rare in the published literature. This was a qualitative study that explored barriers to retention in care of HIV positive children in Nigeria. The study revealed several factors that affect retention in care of children and these were consistent across the all the study sites. Caregiver/parents role is critical to retention in care of children, thus the integration of strategies that identifies and address social and economic challenges in the HIV/AID paediatric care and support are critical in enhancing retention care for HIV positive children.

#### **Recommendations**

Introduction of models care like differentiated care for PLHIV could be an important strategy where mothers of stable children are clustered in their support groups within their communities and reached with drugs supplies of their children for a period of 3-6 months (FHI 360, 2017). Integrating House hold economic strengthening and income generating programmes in the care and support packages is as strategy retention in care. Caregivers can be grouped in savings groups and loaned kick off rotational funds for borrowing to engage in IGAs. Savings groups can be used as paediatric ART pick up clusters for mothers of HIV positive children and a forum for continuous adherence counselling support. There is need for exclusive caregiver's paediatric support groups and to support them to function and encouraging new enrolee caregivers to join and participate in the group's adherence and other related activities. There is need for more research to identify all barriers and apply evidence-based strategies that holistically address the causes to improve paediatric HIV/AIDS care and treatment retention rates. Only a few studies conducted on retention in care of HIV positive children were found. Given the urgent need to increase the retention of children in HIV care, interventions that are effective in increasing adult caregiver PLIHIV in retention should be considered as this child-mother pair model will lead to retention in care of their children. Interventions that target adolescents that are independent of their parents in the ART program should be adopted, tested and implemented. Tracking of caregivers to return their children in care can be enhanced through peer to peer tracking support model. It is also recommended that health facilities that are working in partnership with community-based organisations supported by HIV/AIDS donor agencies for children on ART engage the CBOs to track caregivers during home visits.

## Figures, charts, and tables



Table 1.	HIV/AIDS	comprehensive	treatment sit	tes at Kadun	a states with	study sites	marked	with asteris	sk
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Hospital	Location	Children caregivers	Children on ART	HFs with support groups
Ahmadu Bello University Teaching Hospital	Zaria	9,217	1,259	Yes
St. Gerald's Catholic Hospital	Kaduna North	3,241	453	No
Mothers Welfare Group (Old ABU Campus)	Zaria	834	109	No
**General Hospital Gwantu, Kwoi	Kwoi	4,871	1,101	Yes
General Hospital, Zango Kataf	Zango Kataf	1,970	567	Yes
Army Reference Hospital	Kaduna Central	2,980	421	No
**General Hospital Kachia	Saminaka	1,980	320	No
**Barau Dikko Specialist Hospital	Kaduna central	14,992	3,120	Yes
Louis Hospital Zonkwa,	Zonkwa	1,456	106	Yes
**General Hospital, Kafanchan	Kafanchan	8,923	3,240	Yes
National TB/Leprosy Teaching Hospital	Zaria	3,216	789	No

Source: National Agency for Control of AIDS, (2016); Association for Reproductive and Family Health (2015); Network of people leaving with HIV/AIDS in Nigeria, (2014).

Table 2. Categorization of study groups

Category of participants	Type of facility	Participants	Location		
Adult PLHIV	Adult support group	n=16	Kaduna North and South		
Older HIV/AIDS positive	Health facilities	n=58	Kaduna north and south		
children					
ART clinic Health care workers	Health facilities	n=60	Kaduna north and South		

Site/facility/hosp	Caregi	ivers/	Heal	lth	Older		Populatio		Populatio		Populatio	
ital	Parents (n=16)		care workers		children (n=12)		n %(Male)		n % (Health		n % (children	
			( <b>n=1</b>	5)			care	giver	wor	kers		
	Μ	F	Μ	F	Μ	F	Μ	F	М	F	Μ	F
Fantsuam Support	6	10	-	-	-	-	40	60	-	-	-	-
Group							%	%				
Kafanchan	-	-	10	5	10	2	62	38	67	33	83	17%
General hospital							%	%	%	%	%	
Baraudiko	-	-	11	4	11	1	50	50	73	27	92	8%
Teaching							%	%	%	%	%	
Hospital												
General Hospital	-	-	11	4	3	9	31	69	73	27	25	75%
Gwantu							%	%	%	%	%	
General Hospital	-	-	9	6	1	11	44	56	60	40	8%	92%
Kachia							%	%	%	%		

 Table 3. Participant's characteristics

**Table 4.** Primary and Secondary Data Source Log for review on Medical records for HIV positive children at study sites

Category	Data source	Results	Study instrument
Primary data	Facility registers	Enrolment, tracking, LFT and GOP registers and Log books per facility were	Standardized data Chart abstraction sheet
	Audio recorded FGD responses	167 responses recorded from 134 participants	Questionnaire guide and tape recorders
	FGD transcribed manuscripts	Each word of the participants, including all the fillers were transcribed	Audio recorders with microphones
Secondary data	Systematic Reviews	Citations were identified, Abstracts and full test were retrieved and screened	Cochrane Library
	Medical Databases	Full texts were retrieved	Google, PROMIS, PubMed, Science Direct, Web of Science, Global Health, AMED, CINAHL
	Peer-reviewed literature	Articles with titles and Abstracts were retrieved and screened	Google scholar
	Books	Tittles of books and authors were retrieved	Google books

GH Kafanchan	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
ART Pre-												
Enrolment	65	198	133	5	65	17	17	46	67	93	4	132
Initiated on												
Paediatric ART	88	198	208	2	11	0	17	12	65	93	4	135
Defaulters	21	24	19	0	17	2	5	13	5	9	0	10
Tracked	5	11	0	0	8	0	0	3	4	6	0	6
Lost to follow up	8	11	5	0	7	2	4	5	1	3	0	7
Returned in care	11	4	7	0	8	5	1	1	3	3	0	3
Retained in care	69	187	118	2	10	4	1	37	63	90	4	112

**Table 5.** Aggregated data from Adult PLHIV medical records (Jan-2016 to Dec 2016) at four study sites; GH;Kafanchan; GH; Gwantu; GH; Baraudiko; GH: Kachia

Source: GH Kachia: TH Baraudiko: GH Gwantu: GH Kafanchan: 2016.

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