



# Nigerian health workers' views concerning factors influencing paediatric adherence to anti-retroviral therapy

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Few studies have focused on paediatric anti-retroviral therapy (ART) adherence in Nigeria, probably because of the ethical challenges involved in studying children.

The study aimed to identify factors that influence paediatric ART adherence as perceived by health care workers providing ART services in two cities in Nigeria. Knowledge about such factors would be used to formulate recommendations for enhancing paediatric ART adherence in Nigeria, for facilitating the tasks of the health care workers and for enhancing the ART programme's effectiveness.

An exploratory descriptive qualitative research design was used to identify and to describe health care workers' views in Kano and Lagos, Nigeria. Three focus group discussions were conducted at two clinics that provide free paediatric ARVs (antiretroviral drugs). The transcribed data were analysed by using the framework approach of data analysis.

Health care providers perceived poverty, illiteracy, stigma, discrimination, inappropriate care approaches, and parental dynamics as factors that influence paediatric ART adherence.

Paediatric ART adherence levels in Nigeria could be enhanced by emphasising paediatric ART adherence counselling and by adopting a comprehensive family centred care approach, by improving free paediatric ART services and by empowering parents and reducing stigma and discrimination.

Min studies het al op pediatriese anti-retrovirale behandeling (ARB) nakoming in Nigerië gefokus, wat moontlik toegeskryf kan word aan die etiese uitdagings betrokke by die bestudering van kinders.

Die studie het gepoog om faktore te identifiseer wat pediatriese ARB nakoming kan beïnvloed, soos waargeneem deur gesondheidsdienswerkers wat ARB dienste verskaf in twee stede in Nigerië. Kennis van sulke faktore sal aangewend word om aanbevelings te maak om die pediatriese ARB nakoming in Nigerië te verbeter, om die taak van die gesondheidsorgwerkers te vergemaklik en om die ARM (anti-retrovirale medisyne) program se doeltreffendheid te verbeter.

'n Verkennende beskrywende kwalitatiewe navorsingsontwerp was benut ten einde gesondheidswerkers in Kano en Lagos, Nigerië, se standpunte te identifiseer en te beskryf. Drie fokusgroeppesprekings is gehou in twee klinieke wat gratis ARMs verskaf. Die getranskribeerde data is ontleed deur die raamwerkbenadering tot data analise te gebruik.

Gesondheidsdienswerkers het waargeneem dat armoede en ongeletterdheid, stigma en diskriminasie, ontoepaslike sorgbenaderings en ouerlike dinamika, faktore was wat pediatriese ARB nakoming beïnvloed het.

Pediatriese ARB nakomingsvlakke in Nigerië kan verbeter word deur pediatriese ARB nakomingsberading te beklemtoon, deur die aanvaarding van 'n omvattende gesinsgesentreerde sorgbenadering wat gratis ARB dienste bied, deur die verbetering van ARB dienste, die bemagtiging van ouers en die vermindering van stigma en diskriminasie.

## Introduction

Children on anti-retroviral therapy (ART) are not always retained on the ART programmes (Brackis-Cott *et al.* 2003:258) and parents of children might feel stigmatised by taking their children to ART clinics (Reddington *et al.* 2000:1148). Some parents might be unable to afford expensive antiretroviral drugs (ARVs), and inadequate access to ART could pose challenges.



Nigeria's population exceeds 140 million. According to NACA (2008:8), 3.2 million people were living with HIV in Nigeria in 2007; 136 284 were girls and 142 639 were boys aged 0–14 years. About 507 440 (adults and children) needed ARVs in Nigeria.

Brackis-Cott *et al.* (2003:252) reported that medical providers believed that poverty and stigma were barriers to ART adherence. Many families reportedly struggled with poverty, mental health and substance abuse problems, additional HIV positive family members, and disclosure issues (involving stigmatisation). Bikaako-Kajura *et al.* (2006:s85) reported similar results using in-depth interviews of 42 children on ART, and 42 primary caregivers, in Uganda. In Senegal, Laniece *et al.* (2003:S103) reported that patients who did not pay for ARVs had improved ART adherence levels. Likewise, Veinot *et al.* (2006:261) reported that many patients viewed costs of medications to be barriers to treatment. In Ethiopia, Kloos *et al.* (2007:1) reported that out of 58 405 patients who had started free ART, 46 045 (78.8%) were adherent six months later. Ellis and Molyneux (2007:261) reported that a Malawi ART programme, in a resource-poor setting with only clinical monitoring available, managed to treat children effectively with ART. In Blantyre, Malawi, Van Oosterhout *et al.* (2007:1241) noted that free ARVs improved the programme's quality and reduced the number of ART defaulters. Rosen *et al.* (2007:524) stated that non-drug costs of obtaining treatment, such as transport costs and the loss of income, might limit the access even of free ARVs.

In Nigeria, Mukhtar-Yola *et al.* (2006:141) noted that the most common reason for non-adherence was the inability to purchase more medicines because of financial constraints. This finding agrees with NACA's (2008) assertion that Nigeria's free ARV provision policy implemented in 2006 led to increased access and uptake of ARVs in Nigeria.

### Patterns of paediatric anti-retroviral therapy adherence

Giacomet *et al.* (2003:1398) reported that Italian children who received ART from foster parents were more adherent than those receiving drugs from biological parents or relatives. Tindyebwa *et al.* (2005:171) found that depression and active substance abuse affected ART adherence in adolescents. Mellins *et al.* (2004:1035) suggest that efforts to improve children's adherence to complex regimens require addressing developmental, psychosocial and family factors, which were significantly associated with non-adherence (Mellins *et al.* 2004:1035).

Bekker *et al.* (2006:316) demonstrated that a single community-based public sector ART clinic could provide care to over 1000 patients in an urban South African setting without compromising programme performance. In Kenya, Marston *et al.* (2007:106) concluded that successful ART programmes can be implemented even in extremely challenging social and environmental conditions.

Hammami *et al.* (2004:e591) found that Belgian paediatric ART adherence levels were influenced by the medical information provided to parents and guardians.

### Research problem, objective and question

Although paediatric ARVs are supplied free of charge in Nigeria, optimal paediatric ART adherence rates are not maintained, which impact negatively on the quality of children's lives. The objective of this research project was to identify factors influencing paediatric ART adherence rates in Nigeria, according to health care workers' views. The research question was: 'What factors influence paediatric ART adherence in Nigeria according to the views of health care workers?' Identified factors could be used in recommendations to enhance paediatric ART adherence levels, to facilitate health care workers' tasks and to improve the ART programme's effectiveness.

### Significance of the study

Numerous research reports have been published about ART adherence in many countries. However, limited information has been published about paediatric ART adherence. This study attempted to provide insight into paediatric ART providers' views concerning factors influencing ART adherence in Nigeria. The recommendations provide guidelines for enhancing paediatric ART adherence in Nigeria, and possibly also in other African countries.

### Research method and design

#### Design

The qualitative, descriptive and explorative research design was used to acquire an in-depth understanding of health care providers' perceptions about factors influencing paediatric ART adherence in Nigeria.

#### Population, sample and sampling procedure

Nigeria is the most populous country in Africa and the eighth most populous country in the world, with a population of over 140 million (NACA 2008:6). In Nigeria, most ART paediatric sites are situated within hospitals. It would be impossible to compile a representative sample from Nigeria's vast population of health care workers within a student researcher's budget. As this was a qualitative study, the target population for this study comprised paediatric ART health care providers in Lagos and Kano states at two hospitals that were willing to participate in the study. A non-probability convenience sampling technique was used to select participants for three focus group discussions (FGDs). Each clinic's head requested volunteers to participate in the FGDs. The participants included four doctors (23.5%), 11 nurses and midwives (64.7%), one pharmacy technician (5.9%), and one community health technologist (5.9%). All participants had completed the prescribed training on paediatric ART adherence counselling.

As each hospital's manager requested the health care workers' participation in the focus group discussions,



the researchers had no control over the composition of specific focus groups. Anonymity and confidentiality were guaranteed to participants consequently no differentiations were made according to different health care professionals' contributions. However, all health care professionals shared similar ideas as to factors influencing paediatric ART adherence in their clinics. Initially one focus group interview per site had been planned. Paediatric ART health care providers are very busy people in Nigeria. Consequently, one clinic could not allow all volunteers to participate in one focus group and two separate focus groups had to be conducted at this site.

### Data collection

'A focus group consists of between four and eight respondents who are interviewed together ... in an unstructured or semi-structured way' (Bless & Higson-Smith 2000:110). The major reason for selecting focus group discussions was the desire to obtain insight into groups of health care workers' lived experiences, perceptions and ideas pertaining to paediatric ART adherence in Nigeria. This was based on the assumptions that group interviews can provide more in-depth information than individual interviews and that '... a group's dynamics can generate authentic information' (Burns & Grove 2001:424).

Three FGDs were conducted during August 2009 to September 2009 with a total of 17 paediatric ART health care providers. The second author conducted all the FGDs and obtained permission from all participants to make video recordings, because the researchers considered it desirable to be able to view and listen to the recorded proceedings of each FGD repeatedly. In this way interpersonal interactions and facial expressions could be reviewed time and time again. By using video recordings, the interviewer could focus on the interviewees' interactions, without trying to make comprehensive notes simultaneously.

The major question requested participants to share their perceptions about factors influencing paediatric ART adherence in their clinics. The first question was, 'what are your views regarding ART adherence in children who receive ARVs from your clinic?'

When the ideas stopped flowing the following questions were asked:

- 'What are your views regarding the pattern of adherence to ART in children receiving free ARVs from your clinic?'
- 'What are your views regarding the factors affecting children's adherence to ART in your clinic?'
- 'What could be done to improve adherence to ART amongst children (at your clinics specifically and in Nigeria generally)?'

Further questions were based on the forthcoming discussions, assisting the group to further explore issues raised, or to explain their perceptions in more detail (Bless & Higson-Smith 2000:110). Probing was used by the interviewer to obtain more information about specific aspects raised during the FGD (Burns & Grove 2001:422).

### Data analysis

The framework approach of data analysis, suggested by Pope, Ziebland and Mays (2000:114–116) was used in this study. This approach is similar to the general inductive approach, and is a systematic procedure for analysing qualitative data where the analysis is guided by specific objectives. The primary purpose of the framework approach is to allow research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without imposing restraints by structured methodologies. It aids an understanding of meaning in complex data through the development of summary themes or categories from the raw data ('data reduction'). The five stages of data analysis in the framework approach include familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation.

### Ethical considerations

Permission to collect data was obtained from the Ethics and Research Committee of the Department of Health Studies, University of South Africa, from the departments of the health of the two federal states concerned and from the managers of the two participating clinics. Compliance with ethical standards was achieved because all persons participated anonymously, freely and could withdraw their participation at any stage without any impairment. No report would indicate any specific person's contribution, implying that contributions could not be specified according to the categories of health care workers. Participants were also requested to respect each other's rights to the free expression of their perceptions in a permissive environment that should be non-threatening to all participants. Each participant signed voluntary consent to participate in the FGDs.

The video recordings of the FGDs were kept under lock and key by the interviewer. Only the researchers had access to these videos, the notes taken during the FGDs, and the verbatim transcriptions of the FGDs. Subsequent to the data analysis, the safekeeping of these videos and the verbatim transcriptions was maintained until the research report had been accepted.

### Trustworthiness

Mdondolo, De Villiers and Ehlers (2003:91) elucidated trustworthiness as the extent to which a study is worth paying attention to, worth taking note of, and the extent to which others are convinced that the findings can be trusted. Lincoln and Guba (1985:300) identified a set of criteria (credibility, transferability, dependability and confirmability) that correspond to those typically employed to judge quantitative work.

Credibility standards revolve around activities that increase the trustworthiness of the reported findings (Stommel & Wills 2004:289). The interviewer established prior relationships with the participants. Following the FGDs and the transcriptions, the researchers shared the transcripts



with the respondents for reviews and corrections of the researchers' interpretations of the data.

Transferability, according to Stommel and Wills (2004:288–289), refers to the extent to which findings can be applied to other situations. This study provided in-depth discussions of the nature of the participants, their reported information provided, and the interviewer's observations during the study, methods of data analysis and interpretation of the research findings. The raw data would be available for authorised researchers to cross-check or verify information portrayed in research reports (providing one aspect of an audit trail).

Stommel and Wills (2004:288) maintain that dependability refers to the stability of the data patterns over time or on different occasions. An independent consultant analysed the FGDs' data. The data and analyses were then checked for comparability and similarity, and discrepancies resolved through 'member checking' with the participants.

According to Lincoln and Guba (1985:320–321), confirmability refers to the degree to which the researcher can demonstrate the neutrality of the research interpretations, through a 'confirmability audit' or 'audit trails' (Stommel & Wills 2004:288). The researchers maintained an audit trail that consisted of raw data; analysis notes; reconstruction and synthesis products; process notes; personal notes; and preliminary developmental information.

## Discussion of the results

In this study, four major themes were identified, namely: health workers' views regarding, paediatric ART adherence in children who received free ARVs, ART adherence patterns of children receiving free ARVs, factors affecting paediatric ART adherence and strategies for improving paediatric ART adherence (Table 1).

### Anti-retroviral therapy adherence: Children receiving free antiretroviral drugs

The participants appreciated that adherence was better in children whose parent(s) experienced fewer economic burdens from ART. Scarce resources were required for other expenditures such as transportation, food and other medicines. Paying for ARVs was perceived as an obstacle to accessing quality paediatric ARVs, as stated by a participant:

*'Most of them will not be able to buy the drugs for the kids ... since it is free, the parents come and collect the drugs and give to the kids.'*

(Participant)

Veinot *et al.* (2006:265) and Kloos *et al.* (2007:10) support the perception that free ARVs could enhance paediatric ART adherence levels. Mukhtar-Yola *et al.* (2006:141) reported that the most common reason for ART non-adherence in Nigeria was running out of ARVs and the inability to purchase more ARVs. Ellis and Molyneux (2007:261) studied 238 children on ART in Malawi and reported that 194 (81.5%) were alive and adhering to ART. Twenty (8.4%) of this cohort had died, 19 (8.0%) were lost to follow-up and five (2.1%) had been transferred to other health facilities. Reported evidence from Malawi indicated that free ARVs improved programme quality and reduced the number of ART defaulters (Van Oosterhout *et al.* 2007:1241).

### Anti-retroviral therapy adherence patterns of children receiving free antiretroviral drugs

#### Family centred care approach improved children's adherence to anti-retroviral therapy

The FGD participants explained that children who were accompanied to the clinic by both parents and other siblings adhered better to ART. Through the family centred care approach, family members came into hospital to access all needed services at one stop. A participant explained:

*'It adds value to their adherence treatment in the sense that it removes stress from the parents and caregivers because there is no going up and*

**TABLE 1:** Summary of data analysis of health care workers' views regarding paediatric anti-retroviral therapy adherence. Health workers' views regarding paediatric ART adherence of children who received free ARVs from these clinics.

Research question	Findings from the study
Theme 1: ART adherence in children who received free ARVs	<ul style="list-style-type: none"> <li>The economic burden of ART on parent is instrumental to paediatric ART non-adherence; free ART should enhance adherence.</li> </ul>
Theme 2: ART adherence patterns of children receiving free ARVs	<ul style="list-style-type: none"> <li>Family-centred-care approach improved children's adherence to ART.</li> <li>ART adherence is improved where more than one person in a household was on ART.</li> <li>Children from mother-headed SPHHs adhered to ART better than those from father-headed SPHHs.</li> <li>Children of biological parents presented with higher adherence levels to ART than those from non-biological parents.</li> <li>Parents' literacy levels influenced their children's adherence to ART.</li> </ul>
Theme 3: Factors affecting paediatric ART adherence	<ul style="list-style-type: none"> <li>Parents determined children's adherence levels.</li> <li>Multiple competing factors challenged children's ART adherence abilities:               <ul style="list-style-type: none"> <li>Poverty</li> <li>Inadequate access to quality paediatric ART services</li> <li>Inadequate treatment knowledge</li> <li>Stigma</li> <li>Side effects</li> <li>Parents' forgetfulness</li> <li>Inadequate health system infrastructure</li> </ul> </li> </ul>
Theme 4: Strategies for improving paediatric ART adherence	<ul style="list-style-type: none"> <li>Improved paediatric ART services are fundamental to paediatric ART adherence.</li> <li>The empowerment of parents is essential for improved adherence to ART in children.</li> <li>The creation of jobs and/or income generating projects for the parents would improve their financial situation.</li> <li>Address stigma and discrimination against PLHA in order to improve access to ART.</li> </ul>

Source: Authors' original data

ART, anti-retroviral therapy; ARV, antiretroviral drugs; SPHH, single parent household; PLHA, people living with HIV or AIDS.





*down or even spending of money because they can access the treatment at the same spot.'*

(Participant)

Byrne *et al.* (2002:151) assert that adherence strategies depended on family support and the disclosure issues in households.

### **Adherence improves where more than one person in a household is on anti-retroviral therapy**

The FGD participants explained that children from households with existing members on ART adhered better to treatment. The caregivers in these families had more courage to care for the children, using experiences learned from other family members on ART. A family with more than one person on ART was perceived to be less likely to neglect the child on treatment. Parents provided better adherence support if they had experienced the ART challenges. A participant commented that:

*'it adds value, in the sense that both the parents would be coming together for treatment at the same time and would put it in their mind that they have something important to do.'*

(Participant)

However, FGD participants explained that parents sometimes felt enough attention should be focused on caring for the healthy children. Such parent(s) thought the children living with HIV were in effect 'lost causes' and needed to be left alone. A participant commented:

*'... they [caregivers or parents] may say, take your drugs, if you like you take it, if you don't like don't take it; so, that may be some form of neglect that would segregate the other children to leave this one part.'*

(Participant)

Brackis-Cott *et al.* (2003:252) note that any family with more than one HIV positive member placed excessive burdens on caregivers and parents, resulting in poorer adherence to ART. Marhefka *et al.* (2006:435) maintained that caregivers' psychological distress, arising from excessive burdens on caregivers and parents, influenced children's ART adherence levels. Interventions and reducing caregivers' stress levels might help to improve adherence.

### **Children from mother-headed single parent households (SPHH) adhere to anti-retroviral therapy better than those from father-headed SPHH**

FGD participants explained that single mothers were better caregivers to children on ART than single fathers. The health care workers added that single mothers required a steady income in order to access ARVs and for nutritional supplements for the child. They argued that fathers were always too busy and spent more time outside the home, as explained:

*'I know a particular family. The man does not believe that there is anything like HIV ... so it's the mother that sneaks in occasionally when he is not there and administers the drugs; if the man is around, he will not agree.'*

(Participant)

Some FGD participants viewed children under the care of single fathers as often being neglected, as stated: *'If the mother is left with the child, it is harder because family pressure and most*

*times her poor financial situation will have adverse effects on the child.'*

### **Biological parents' children present with higher anti-retroviral therapy adherence levels than those of non-biological parents and guardians**

FGD participants from one clinic remained inconclusive regarding paediatric ART adherence in biological and non-biological parent and caregiver homes. FGD participants from the other clinic reported that children of biological parents presented with better ART adherence levels than those from non-biological parents. Highlighting stigmatisation against children of non-biological caregivers, one FGD participant said:

*'... they may think that it is all of us that are having this problem O, I beg don't make anybody to look at me with a bad eye ...'... 'They will say that I'm not your parent and we don't know where you are coming with this thing [AIDS]. They even name this child and all the people in the compound will know the type of illness that the child is going through.'*

(Participant)

The findings of the South African study carried out by Greeff *et al.* (2008:96), were similar. These authors reported that the mere fact that a spouse, child or family member was related and associated with PLWA led to stigmatisation. Children from other families were prohibited from associating with those from affected families.

On the other hand, Giacomet *et al.* (2003:1402) noted that children receiving therapy from foster parents were more adherent than those receiving drugs from biological parents or relatives. Univariate analyses by Marhefka *et al.* (2006:429) showed that an adherent classification (at least an 80.0% refill rate) was associated with having non-biologically related caregivers. Likewise, Williams *et al.* (2008:e1751) report that when an adult other than the biological parent were the primary caregiver, there was an associated improved adherence.

### **Parent's literacy levels influence their children's adherence to anti-retroviral therapy**

Paediatric ART adherence rates were reportedly higher amongst children with better educated parents. Education in this sense referred to passing through at least a primary school. A participant commented: *'If the caregivers are aware or are educated about the medications I think they will be able to cope and the child will be able to adhere with the drugs.'*

Wachholz and Ferreira (2007:S424) reported that education of caregivers was associated with better ART outcomes as did Martin *et al.* (2007:61) and Williams *et al.* (2008:e1753).

### **Factors affecting paediatric anti-retroviral therapy adherence**

The third theme that emerged from the data concerned factors affecting paediatric ART adherence.

#### **Parents as determinants of adherence in children**

FGD participants explained that parents were the main determinants of paediatric ART adherence, making



the parents, and not the children, targets for adherence counselling training. They also recognised the need for continuous and re-enforced adherence counselling to families by stating: *'If you don't involve the caregiver or parent [in the child's care], you cannot achieve good results because they are the ones monitoring these children at home.'*

Martin *et al.* (2007:66) concluded that responsibilities for medication-related tasks should be clarified amongst family members, such as parents. Regimen knowledge should be emphasised and caregivers should avoid assigning treatment responsibilities to a child prematurely. Pontali (2005:143) recognised the need for tailoring ART regimens to the daily activities of the family, considering the strategic position of the parent in the child's adherence programme. On the other hand, Mellins *et al.* (2004:1035) argued that in logistic regressions controlling for age, caregiver and family factors were the most strongly associated with non-adherence. These included worse parent-child communication, higher caregiver stress, less disclosure to others and less quality of life.

### Multiple competing factors challenge children's abilities to adhere to anti-retroviral therapy

The FGD participants recognised access, poverty, stigma and discrimination, inadequate knowledge, and irregular availability of paediatric drug formulations as factors limiting paediatric ART adherence.

FGD participants perceived that children experienced low ART adherence rates because of the effects of the parents' poverty. These included lack of funds to pay for transport and medical bills (other than free ARVs). Some participants stated:

*'They are jobless, they don't have anybody. There is no helper, so, because of that, they may not come when it is their due time to come for their drugs.' ... 'We see some of them here, they will tell you madam, the money is not there, I don't have money for transport today that's why.'*

(Participant)

Rosen *et al.* (2007:524) reported that non-drug costs of obtaining treatment might limit access, despite free ARVs. Kip, Ehlers and Van der Wal (2009:6) also argued that economic issues do affect ART adherence rates even if the ARVs are supplied free of charge. Caregivers also spend time and money to visit clinics.

Ware *et al.* (2009:0039) reported that parents whose children were taking ART overcame economic obstacles by prioritising adherence: borrowing and begging transport funds, allocating resources in favour of treatment, and doing without some necessities such as food.

The FGD participants reported that inadequate access (such as living far from a clinic) to quality paediatric ART services caused drawbacks in paediatric ART adherence. Participants indicated that the patients received one month's ARVs, whilst they preferred to receive 2–3 months' stock, as explained by a participant: *'Currently, the duration is approximately one month*

*for the longest duration and coming back at such close interval presents a challenge in terms of transportation costs.'*

Accessibility to quality AIDS care and medications was one of the most significant barriers to adherence in Nigeria (Mukhtar-Yola *et al.* 2006:144). ART adherence levels can be maintained even in resource-limited settings (Ellis & Molyneux 2007:261) where the lack of laboratory facilities, staff and paediatric drug formulations, did not prevent the commencement of ART for Malawi's children. Likewise, Marston *et al.* (2007:106) reported that the response to ART in a slum population was comparable to that seen in industrialised settings. These reports indicate that resource-poor settings did not necessarily imply poor paediatric ART adherence rates.

Inadequate knowledge of ART also contributed to lack of paediatric ART adherence as explained by one participant: *'Each and every day to be taking drugs? Kai! I cannot do that, Kai! Let me go to native ... once, twice, when I take, it will disappear.'*

Marhefka *et al.* (2004:323) reported that significant regimen knowledge deficits were significantly associated with low ART adherence levels. Tindyebwa *et al.* (2005:175–176) identified that in many Sub-Saharan African countries, health practitioners were inadequately prepared to address the needs of HIV-infected children.

Fear of the unknown might contribute to stigma and discrimination. Some parents and guardians did not collect ARVs from their nearest clinics, others failed to administer the ARVs as prescribed. They feared that people around them might detect the child's HIV status from the labels on the medicine bottles. A participant commented:

*'Let's say it's time for the mother to administer the drug and there is a third party around and let's say the person is even educated. He can read the label on the bottle. She may not be able to administer the drug at that time because of that fear of stigma. That third party may go and broadcast the type of drugs the child is taking. So, she'll not administer the drug.'*

(Participant)

Bikaalo-Kajura *et al.* (2006) reported that stigma remained a barrier to adherence even for children who had complete disclosure and a supportive relationship with at least one parent. Kip *et al.* (2009:6) also noted that low literacy levels and stigmatisation impacted negatively on ART adherence, and impacted negatively on regular clinic attendance and ART taking in Botswana (Kip *et al.* 2009:6).

FGD participants reported that side effects contributed to paediatric ART non-adherence. In their opinions, children disliked ARVs because they were unpalatable, caused vomiting and other side effects. A participant explained:

*'There was a mother that was telling me that whenever it is eight in the evening, the child used to run and hide himself because whenever they give him the drugs, he used to vomit.'*

(Participant)

Heath *et al.* (2002:211) reported that out of 638 subjects in Canada, 70 (11.0%) reported intentional non-adherence



with between 4.0% and 7.4% reporting this activity over the preceding year. Those subjects who reported at least one severe symptom were more than twice as likely to report intentional non-adherence. Each additional symptom requiring clinical action was associated with a 25.0% increase in the risk of intentional non-adherence.

Some parents and caregivers forgot to administer ARVs to their children. Others forgot to turn up for ARV refills at the hospital, thus, ran out of medicines. A participant commented: *'Some parents forget the actual time, maybe they will be busy doing something till the time to administer the drug will be over.'*

Ammassari *et al.* (2002:S126) reported that the most common reasons why patients missed ARVs included forgetfulness (30.0%–66.0% of participants), the complexity of medication regimens (7.0% – 52.0%), difficulties in integrating treatment schedules into their daily activities (36.0% – 57.0%), fears of side effects (13.0% – 42.0%), and worries about HIV disclosures (14.0% – 33.0%).

Health care workers perceived their health systems' infrastructure to be overstretched by the increasing number of paediatric ART patients. The few trained members of staff were transferred from the paediatric ART clinic to other units or facilities, resulting in further staff shortages and burnout of the remaining few. Participants emphasised that health service managers should recognise challenges inherent in their programmes and resolve them early, in order to improve the quality of services. They cited the following challenges:

- *'Staff shortage and consulting rooms' challenges.'*
- *'The workload is too much.'*
- *'Transfer of trained counsellors to other units or other facilities.'*
- *'We used to run two clinics per week ... now, from Mondays to Fridays, we run clinics.'*

The attainment of patient satisfaction with ART services was challenged by many doctors and nurses, faced with low pay and poor working conditions. They were seeking jobs in industrialised countries (UNICEF, 2005:8). Van Oosterhout *et al.* (2007:1245) report that despite the human resource crisis in the health care system, remarkable improvements in the quantity and quality of care could be achieved.

### Strategies for improving paediatric anti-retroviral therapy adherence

The fourth theme that emerged from the data analysis concerned strategies for improving paediatric ART adherence, including the improvement of paediatric ART services, the empowerment of parents and the addressing of stigma and discrimination against people living with HIV or AIDS (PLHA).

#### Good services are fundamental to paediatric anti-retroviral therapy adherence

FGD participants indicated that improving the quality of ART services was important to patients, staff, and the organisation. They explained that these included staff training and retention, provision of comfortable workspaces

such as adherence counselling rooms, and disclosure of the type of drug the child was taking. Other quality improvement strategies included reducing staff burnout by spreading workloads evenly amongst staff, providing high quality information and education to clients and caregivers, and reducing the dosing and number of drugs through switching to ARV combination therapies. A participant explained:

*'The quality of information we give ... counts a lot on how they listen to us and it will have a bearing on the quality of adherence.'*

(Participant)

FHI (2004:349) suggested similar strategies to improve adherence and patient retention: educate and motivate patients, provide basic drug information, discuss the importance of adherence, timing of medication, provide knowledge about possible drug interactions, simplify drug regimens, tailor treatment to the patient's lifestyle, use an adherence team, address patient-related issues, recruit an adherence monitor, provide adherence promoting devices, use home-based care staff to promote adherence and use the adaptation of directly observed therapy (DOT).

#### Empowering parents improves children's anti-retroviral therapy adherence

FGD participants recognised that most parents of children on ART were resource-limited. They called for educational and economic empowerment of caregivers and parents to support paediatric ART adherence. These, they suggested, should include income generating activities for the parent and caregivers, re-enforced adherence counselling, provision of job opportunities for caregivers, payment of re-imburements to the parent and child for transportation and food and re-enforced community care programmes, especially support group activities as a way of empowering caregivers. A participant commented: *'Each time they come to the clinic there should be an on-going adherence counselling to see how they can talk about it.'*

Brackis-Cott *et al.* (2003:252) concluded that adherence to ART was a long-term, on-going problem directly tied to the family life of the child, requiring that the parent should be empowered with a sustainable capacity to maintain the child throughout life.

#### Address stigma and discrimination against people living with HIV or AIDS in order to improve access to anti-retroviral therapy

This referred to the provision of easy and convenient ways of receiving treatment without undue fears of the unknown, stress or pressure to children and families. FGD participants indicated that the lack of access was not only as a result of the absolute distance from home to the nearest ART centre. They argued that it also included the distance from home to a location or ART centre that the family felt more comfortable attending. Parents were more comfortable with health facilities where they were unknown. They also demanded that ARV refills should be for 2–3 months, to reduce the burden associated with frequent travels. One participant elucidated:





*'As long as it [HIV status] remains a secret between the patient and the doctor, I think the problem [of lack of adherence] will continue ... if we can remove the issue of stigma, so that more people will become aware of this, then there will be a lot of improvement.'*

(Participant)

Byrne *et al.* (2002:151) suggested that adherence strategies devised by families depended heavily on family support and the resolution of disclosure issues within households. Veinot *et al.* (2006:266) noted that children might need support for managing difficulties with treatments such as side effects, social impacts, and adherence. Nabukeera-Barungi *et al.* (2007:130) recommend that parents and caregivers should be encouraged to disclose the child's status to at least one other person before starting ART.

## Limitations of the study

The transferability of the study's findings is limited by the fact that only 17 health care workers participated in the FGDs conducted during this study. Therefore, the findings arising from the study might not be transferable beyond these two paediatric ART clinics. Only FGDs were used to collect data. Different results might have been obtained if quantitative structured interviews had been conducted with the health care providers, and/or if checklists had been completed about observations during paediatric clinic visits, and/or from paediatric patients' records. The results portray the perceptions of only the health care providers and not those of the caregivers and parents or of the paediatric ART patients themselves, because permission to conduct interviews with patients, especially with paediatric patients, is granted only in exceptional cases in Nigeria.

## Recommendations

The recommendations will be categorised according to those benefiting the patients, the health care professionals and the ART programme.

### Enhancing patients anti-retroviral therapy adherence levels

Stable paediatric ART patients should receive three months' supplies of ARVs, instead of monthly supplies. This could help to reduce the burdens of transportation

Stigma reduction and family disclosure and integration programmes should be instituted. This should enable parents and caregivers to collect ARVs from their nearest local clinics rather than from more distant clinics to avoid recognition by their community members.

Encourage the biological parents of CLWHA to personally assume responsibility for ensuring the child adheres to ART. Encourage all family members, especially, those on ART, to participate in paediatric ART adherence programmes of the family. They should serve as treatment supporters for the child on ART.

## Improving the services rendered by the health care providers

A critical mass of health care workers and caregivers should be trained on paediatric ART adherence, to cope with the increasing demands for paediatric ART services.

## Improving the anti-retroviral therapy programme

Adopt a paradigm shift from a family centred care approach (FCCA) to a comprehensive family centred care approach (CFCCA). This entails looking beyond the family's health problems to economic, psycho-social, civil, religious, and cultural or any other factors that might impact on paediatric ART adherence.

Strengthen linkages between the health facility and community-based programmes that include income-generating activities for parents and caregivers, and care for orphans and vulnerable children. Others include parental empowerment programmes, food and nutrition, education, water and sanitation, basic health care and psychosocial support programmes.

Mainstream adherence counselling should be consistently provided at all points of service delivery so that clients' families will receive the same adherence counselling and treatment messages at every point of service. Develop and implement targeted treatment education and adherence counselling programmes that are culturally sensitive and adapted to parents' and caregivers' individual differences.

## Conclusion

The participating health care providers perceived poverty, illiteracy, stigma and discrimination, inappropriate care approaches, and parental factors as major factors influencing children's ART adherence. Mainstreaming adherence paediatric ART counselling and adopting comprehensive family centred care approaches could improve paediatric ART adherence. Other measures suggested included quality improvement of paediatric ART services, parental empowerment and stigma and discrimination reduction programmes.

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## Authors' contributions

R.C. was the project leader as this study was conducted for his MPH degree. V.J.E. made substantive academic contributions to the study from its inception till its completion, as the





supervisor of R.C.'s master's dissertation. V.J.E. wrote the article, based on the master's dissertation, in conjunction with R.C. V.J.E. revised the article and managed the submission process as the corresponding author. R.C. conducted the focus group discussions, but analysed the data with inputs from V.J.E. R.C. wrote the research report (dissertation) with guidance from V.J.E.

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