

Original Research Article

What needs do HIV Infected Nigerian Children and Their Care Givers Expect to Be Met by Their Paediatric Anti-Retroviral Clinics?

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ABSTRACT

Background: Paediatric HIV disease is a chronic infection requiring frequent and lifelong follow up care. The felt needs of HIV infected children and their caregivers attending Nigerian paediatric ARV clinics are unknown. These needs ought to be known in order to enhance ART service delivery.

Objective: To determine the felt needs of HIV infected children and their care givers attending the paediatric ARV clinic of a Nigerian paediatric ARV clinic.

Methods: Consecutive consenting HIV infected children and their care givers seen at the Paediatric ARV clinic of Ladoke Akintola University of Technology Teaching Hospital Osogbo, Western Nigeria, over a one year period were studied. Information concerning the felt needs of the HIV infected children and their caregivers, were sought and recorded in a proforma. The data obtained was analysed using SPSS version 16

Results: Thirty two HIV infected children and their care givers were studied over the one year period. The care givers were the mothers in 25(78.1%) and fathers in 7(21.9%) cases. The ages of the children studied ranged from 9 months to 12years, with a mean \pm SD of 6.1 ± 3.0 years. The ages of the fathers ranged from 34-70 years with a mean \pm SD of 43.9 ± 12.6 years, while the range was 27-44 years with a mean of 34.7 ± 7.9 years for the mothers. All the children and their care givers wanted free hospital services and required for the government to continue subsidizing cost of basic investigation such as chest radiographs and routine full blood counts tests done in conjunction with CD4 counts, while 18(56.3%) wanted the assistance of health care providers in disclosing the HIV status of their HIV infected children. Ten(31.3%), 9 (28.1%), 4(12.5%) and 3(6.3%) children and their care givers wanted the health facility to commence special afternoon clinics, prompt delivery of health care services, increased interval from once in two months clinic appointments to once in three months and more user friendly services.

Conclusion: HIV infected children and their caregivers have formidable needs. Addressing these needs should improve utilization of paediatric ARV services.

Keywords: Expectations, needs, desires, carers, HIV and paediatrics.

INTRODUCTION

Human immunodeficiency Virus infection continues to be a worldwide concern with global estimates revealing that the number of people living with HIV increased from 31.7 million to 37.9 million between year 2010 and 2018. Of the 37.9 million people, 1.7 million are children

under the age of 15 years. ^[1] Nigeria has a fair share of the paediatric HIV disease considering the fact that it is the most populous African nation. ^[2] Currently the lifelong need for care of HIV infected individual and the caregivers puts a lot of demand on the health system and those accessing the care.

The paediatric ARV clinic at Ladoke Akintola University of Technology Teaching Hospital runs weekly, between the hours of 8:00a.m and 3:00pm on Tuesdays and Thursdays. The services provided in the clinic comply with the national recommendations for care. [3] These services provided on a weekly basis range from health talk, to consultation with a doctor, laboratory investigations, adherence counselling and collection of prescribed drugs at the pharmacy. The services are provided on a first come first served arrangement to ensure orderliness and fairness. Follow up clinic is a fortnight for those initiating HAART and 2 monthly for children on HAART or Cotrimoxazole or isoniazid preventive therapy.

The views of HIV infected children and their care givers on paediatric ART services provided in Nigeria are unknown. However it is important to find out their expectations, as well as their opinions of the standard of care provided. This is with a view to assess the level of consumer satisfaction. The desire to conduct this study was borne out of this. This information is also expected to be a vital resource for health care planners and health providers. It is expected to help them formulate appropriate strategies and interventions that will help modify and improve the services delivered.

METHODOLOGY

Consecutive consenting HIV infected children and their care givers seen at the Paediatric ARV clinic of Ladoke Akintola University of Technology Teaching Hospital, Osogbo, Nigeria between 1st of July 2014 and 30th June, 2015 were studied. Information was obtained by using a non-structured questionnaire. Some of the details obtained include socio-demographic profile of the children and their parents. Other details sought include what the children and their care givers felt was lacking in the services provided and what they felt could be done to improve the services.

The educational attainments of the parents were classified as either primary, secondary or tertiary school or equivalent accomplishments. The occupations of both parents were noted and socioeconomic classification of the parents was computed and based on the occupation and educational status of the parents as classified by Oyedeji et al. [4] Social classes of the children were determined by allotting scores for the different occupational and educational attainments which were summed up and the mean of the final score was equivalent to the different social classes. Social classes I and II were further sub-classified to give the upper social class and social class three the middle and social class IV and V the lower social class, based on Oyedejis socio economic classification. [4]

The information obtained was imputed into a personal computer and analysed using SPSS version 16. Categorical data was expressed as percentages, while age was expressed as means and ranges. [5]

RESULTS

General characteristics

A total of 32 children and their parents were studied. The care givers accompanying the children to the clinic were their biological parents. The care givers were the mothers in 25(78.1%) and fathers in 7(21.9%)

Age and sex distribution of children studied

The ages of the children studied ranged from 9 months to 12years. The mean \pm SD age of the children studied was 6.1 \pm 3.0. Fifteen (46.9%) of the 32 children were aged between 9months and 5years, while 14(43.8%) were aged between 6 - 10years and 3(9.4%) between 11-15years. Of the 32 children studied 14(43.8%) were boys and 18(56.2%) girls giving a male to female ratio of 1.0: 1.3. The age and sex distribution of the children studied is shown in Table 1

Age distribution of the parents

The ages of the fathers ranged from 34-70 years with a mean of 43.9 ± 12.6years, while the range was 27-44 years with a mean of 34.7±7.9 years for the mothers.

General expectations of health care users from the services provided

Of the 32 children studied 6(18.8) gave no suggestions as to what they would desire to see or change in the clinic, while 2(6.3%) were satisfied with the quality and content of the care provided. The remaining 24(75.0%) gave suggestions to what they desired. Some of the respondents had more than one issue they wanted addressed.

Parental training or educational attainments

Two (6.3%) among the fathers had no formal training 4(12.5%) had only primary school and equivalent training, 5(15.6%) had secondary school and equivalent training, while the remaining 21(65.6%) had tertiary educational training. Concerning the mothers 4(12.5%) had no formal education training, 6(18.8%) received primary school training and equivalents, 5(15.6%) had secondary school and equivalent training and the remaining 17(53.1%) had tertiary and equivalent institution training.

Occupational categories of parents

Of the 32 fathers studied, none was unemployed, 13(40.6%) were artisans, 9 (28.1%) were in the category of the police officers, school teachers and nurses, while 2(6.3%) were in the categories of lecturers in the polytechnics and journalists. The remaining 8(25.0%) fathers were in the categories of accountants, engineers, lawyers, medical doctors, bank managers, university lecturers and chairmen of big corporations. Concerning the mothers studied, 2(6.3%) were students, 19(59.4%) were hairdressers, medium grade traders and 5(15.6%) belonged to the category of school teachers, nurses and police officers, while 3(9.4%) belonged to the category of lecturers in polytechnics and technical school and the remaining 3(9.4%) belonged to the category whose parents were

professionals such as accountants, managers and big corporation managers.

Social classes of the children studied

Of the 32 children studied 3(9.3%) were from social Class I, 10(31.3%) from social class II, 11(34.4%) from social class III, 7(21.9%) from Social Class IV and 1(3.1%) from social class V. Thus 13(40.6%) children were from the upper social class, 11(34.34%) from the middle class and 8(25.0%) from the lower social class.

Specific expectations of the patients and their care givers.

All patients and their care givers wanted the government to continue subsidizing care of services, and provide free baseline chest radiographs for all patients and routine full blood counts tests done in conjunction with CD4 counts. (Both full blood count tests and baseline chest radiographs were initially done free of charge at the inception of the clinic but were later paid for by the patient, because of reduced funds from the hospital implementing partners such as the federal government and international organizations)

Most of the patients and their care givers wanted their health care providers to run clinics in the afternoon or at other convenient times in order to allow the HIV infected children attend school and the care givers or their parents attend to their vocation. Of the 32 children only 1(3.1%) of the parents had disclosed the HIV status of their child. Eighteen caregivers required the assistance of their doctors in disclosing the HIV status of their unaware infected child. Other common desires were for reduced waiting times, prompt and improved services. Some of the patients had more than one expectation, while a few were satisfied with the services provided. The details of the expectations of the health care users are shown in Table II

Table 1: Age and sex distribution of the children studied

Age group	Gender	
	Male	Female
> 9months – 5 years	6	9
> 5 years – 10years	6	8
> 10 years – 15 years	2	1
Total	14	18

Table 2: Expectations of the studied HIV infected children and their caregivers

Expectation	Number (n= 32)	Percentage of 32
Government subsidy on cost of care provided at ARV clinic	32	100
Requiring assistance of doctors in disclosing HIV status to child	18	56.3
Desire for afternoon clinic	10	31.3
Improvement in health care service delivery/ prompt service delivery with reduced waiting times	9	28.1
No answers provided	6	18.8
Longer interval between clinic appointments	4	12.5
Cure for HIV	4	12.5
Do not know or no idea	3	9.4
More friendly user health services	2	6.3
Require assistance of the health providers to get a job	2	6.3
Confidentiality of status and care procured/obtained by service providers	2	6.3
Completely satisfied with the service provided	2	6.3
Paediatric –ARV clinic to commence operation as early as 7:00am	2	6.3
Financial assistance required	1	3.1

DISCUSSION

Majority of the children infected with HIV and their care givers had many needs as shown in this study. Government subsidy on cost of care, prompt delivery of services and review of clinic time were top on the list of required improvements by the HIV infected children and their care givers. Most of the previous studies on expectations or needs of paediatric HIV children and their care givers focused on other aspects such as nutrition, psychosocial, schooling and neuro developmental needs, thus indicating that the suggested improvements in the present study is original. [6-8]

Government subsidy was the most common expectation in this report and this might have arisen from the withdrawal of support and cuts from international organizations. All baseline tests, such as chest radiograph CD4 counts and full blood and routine blood counts were provided free at the inception of the clinic and the first couple of years after establishing the clinic. In the last 5 years or thereabout, patients have had to pay for baseline chest radiograph and full blood counts at follow up. These investigations can cost between \$2 -5 which is an enormous cost in a country where most families are poor and earn less than a dollar a day.

Disclosure of HIV infection status to the children was also another issue where care givers needed assistance. Previous studies have shown that disclosure is a very sensitive matter in children and can be associated with stigmatization if the results

are not disclosed discreetly. [9,10] Some caregivers or parents who were HIV infected also were apprehensive that their own status was at the risk of being indiscreetly disclosed by the health care providers residing in their community. Indiscrete disclosure of the HIV status of an individual is unethical. Therefore, there is a need to train and re-train health workers managing HIV infected children on disclosure with emphasis on confidentiality and the need to exhibit medical ethics and professionalism in the disclosure of results. [3]

Another important expectation was a need to change the time of the Paediatric ARV clinic to periods convenient for the patient and care givers. This request was borne out of the fact that HIV infected children and their care givers were missing school or work respectively on the day they attended clinics. Previous studies support the fact that poor educational performance is associated with absenteeism among HIV infected school children [6,7] Sickness on the part of the HIV infected child was the predominant reason for school absenteeism in the previous studies. It is however worthy of note that the time taken for consultation with the time to commute to and from the health facility may be up to 4-7 hours, which can itself be responsible for missed school or work days. This often affects the accompanying care givers vocation also. Thus, most of the studied population requested for afternoon clinics and one of the respondents requested for early morning

appointment as early as 7:00am on clinic days.

Closely related to this issue of reviewing the time for the clinic for convenience of the patient, is the fact the paediatric clinic visits are scheduled at a frequency of every two months as detailed on the national guideline.^[11] This frequency of clinic visits does not match the frequency in HIV infected parents, who are scheduled for follow up clinics at 3-4 monthly intervals.^[3] However, the current national guidelines for treatment of HIV recommend an integrative approach to the management of children and their caregivers. Disparities in the follow up intervals of the children and their parents who are adults are a challenge. Thus, there is a need for the Nigerian Federal Ministry of Health to revisit and harmonise the follow up schedules in both adults and children.

Another related issue with respect to the setting up of convenient times for the clinic appointments is the expectation for faster delivery services. The reason for this expectation is to reduce time wastage at the health services and spend the time saved at other productive activities. As outlined above time wastage may contribute to time missed at school and work by the children and their caregivers respectively. Thus there is a need for the service providers to have a meeting and discuss the possibility and practicality of reducing the time wasted during clinic activities.

A user friendly service was also an important expectation as a few of the care givers complained of some of the staff not been very friendly. There is a need for health care professionals to be warm and friendly. This is expected to gain the confidence of the patient and allow the patient to express their desires. Previous studies show that when the health care providers are friendly and respectable, health care service patronage is better and the health users give better information which in turn helps health providers to come out with more effective management strategies or plans.^[12,13]

The remaining care givers, who expected financial support and a job, probably reflect the harsh prevailing economic situations in the country. There is a need for government to stand up to its responsibilities of good governance, including making jobs available for those willing to work. The government should aim to improve the economy by better management through the finance ministry. Poverty alleviating strategies should also be put in place by the government.

CONCLUSION

It is concluded that HIV infected children and their care givers have many expectations. Concerted effort needs to be put in place by the health care providers to meet these expectations in order to keep the health care users happy and improve patronage. Health providers should continuously seek to know what their consumers expect of them and consider whether or not these are reasonable and achievable in the context of their own practices. Provision of felt needs should strike a reasonable balance between effectiveness and consumer satisfaction.

REFERENCES

1. UNAIDS. The Gap Report 2014- children and pregnant women living with HIV[internet]. Joint United Nations Programme on HIV/AIDS. [Accessed 2019 Sep 26]. Report No: UNAIDS / JC2656. Available from: <http://www.unaids.org/sites/default/files/media_asset/09_ChildrenandpregnantwomenlivingwithHIV.pdf>.
2. Ojeniran MA, Emokpae A, Mabogunje C, Akintan P, Hoshen M, Weiss R. How are children with HIV faring in Nigeria?--a 7 year retrospective study of children enrolled in HIV care. *BMC Pediatr.* 2015;15:87. doi:10.1186/s12887-015-0405-9
3. FMOH. National Guidelines for HIV prevention Treatment and Care, Federal Ministry of Health, HIV/AIDS division, Abuja, Nigeria. 2016 [Online] available at <http://apps.who.int/medicinedocs/documents/s23252en/s23252en.pdf> accessed on 13/09/2019

4. Oyedeji GA. Socio-economic and cultural background of hospitalised children in Ilesa. *Nig J Peadr* 1985; 12: 111 – 117
5. SPSS Inc. Released 2007. SPSS for Windows, Version 16.0. Chicago, SPSS Inc. <http://www-01.ibm.com/support/docview.wss?uid=swg21476197>
6. Anabwani G, Karugaba G, Gabaitiri L. Health, schooling, needs, perspectives and aspirations of HIV infected and affected children in Botswana: a cross-sectional survey *BMC Pediatr*. 2016; 16: 106. 22. doi: 10.1186/s12887-016-0643-5
7. Punpanich W, Detels R, Gorbach PM, Leowsrisook P. Understanding the psychosocial needs of HIV-infected children and families: a qualitative study. *J Med Assoc Thai*. 2008;91Suppl 3(Suppl 3):S76–S84.
8. Sherr LL, Croome N, Castaneda KP, Bradshaw K, Romero RH Developmental challenges in HIV infected children- An updated systematic review. *Children and Youth Services Review*. 2014; 4574-89
9. Ehiri JE, Alaofè HS, Yesufu V, Balogun M, Iwelunmor J, Kram NA-Z, Lott BE, Abosede O. AIDS-related stigmatisation in the healthcare setting: a study of primary healthcare centres that provide services for prevention of mother-to-child transmission of HIV in Lagos, Nigeria *BMJ Open* 2019;9:e026322. doi: 10.1136/bmjopen-2018-026322
10. SukranKose, AliyeMandiracioglu, GulsenM ermut, FigenKaptan, Yusuf Ozbel. The Social and Health Problems of People Living with HIV/AIDS in Izmir, Turkey. *5Eurasian J Med*. 2012;4:32–39. doi: 10.5152/eajm.2012.07
11. Federal Ministry of Health Nigeria. National Guidelines for Paediatric HIV and AIDS Treatment, Care and Support. 2010.
12. Tessema SB, Adane MM. Assessment of antiretroviral treatment (ART) care service provision in Tigray Region health centers, North Ethiopia. *BMC Health ServRes*. 2015; 15:368. doi: 10.1186/s12913-015-1032-8.
13. Dagne T, Tessema F, Hiko D. Health service utilization and reported satisfaction among adolescents in Dejen District, Ethiopia: a cross-sectional study. *Ethiop J Health Sci*. 2015;25:17–28. doi:10.4314/ejhs.v25i1.4

How to cite this article: Oyedeji O.A. What needs do HIV infected Nigerian children and their care givers expect to be met by their paediatric anti-retroviral clinics? *Int J Health Sci Res*. 2019; 9(10):119-124.
