



ISSN: 2476-8642 (Print)

ISSN: 2536-6149 (Online)

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Annals of HEALTH RESEARCH

(The Journal of the Medical and Dental Consultants' Association of Nigeria, OOUTH, Sagamu, Nigeria)

Volume 12 | No. 1 | Jan. - Mar., 2026



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**PUBLISHED BY THE MEDICAL
AND DENTAL CONSULTANTS ASSOCIATION
OF NIGERIA, OOUTH, SAGAMU, NIGERIA.**

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Annals of Health Research

(The Journal of the Medical and Dental Consultants' Association of Nigeria, OOUTH, Sagamu, Nigeria)

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Volume 12, Issue 1: 66-75

March 2026

doi:10.30442/ahr.1201-06-316

ORIGINAL RESEARCH

Association of Sociodemographic and Clinical Factors on Health-Related Quality of Life of Children Living with HIV in Lagos, Nigeria

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Citation: Alakaloko AE, Akinsete AM, Oyenusi EE, Esezobor CI. Association Of Sociodemographic And Clinical Factors on Health-Related Quality of Life of Children Living With HIV in Lagos, Nigeria Ann Health Res. 2026;12(1):66-75. doi:10.30442/ahr.1201-06-316.

Abstract

Background: Children living with the human immunodeficiency virus (CLHIV) now survive well into adolescence and adulthood due to the efficacy of antiretroviral therapy. Hence, health outcomes of interest now include their quality of life and factors that may affect it.

Objectives: To determine the relationship between HRQOL of children with HIV and socio-demographic/clinical factors. To identify the association between psychological distress in the caregiver and caregiver's reported HRQOL of the children.

Methods: A descriptive cross-sectional study. One hundred CLHIV and their caregivers were studied. A general questionnaire was used to obtain information on social demographics and medical history. Participants' HRQOL was determined using the PedsQL inventory version 4.0. The General Health Questionnaire (GHQ) was used to screen for the presence of psychological distress in caregivers.

Results: Age and sex did not significantly affect the HRQOL, however, socioeconomic class significantly affected the HRQOL as children of caregivers in the upper socioeconomic class (I-III) had higher mean composite HRQOL scores compared to those in the lower socioeconomic class (IV-V) for the parent report. (88.08 ± 11.65 v 78.71 ± 23.69 ; p value < 0.017). Being an Orphan significantly affected the HRQOL of the children for the parent report as the parent reported a lower HRQOL for these children (81.79 ± 17.73 v 88.20 ± 12.68 ; p-value 0.046).

Psychological distress was present in 23% of the caregivers. However, the HRQOL score was similar between children whose parents had reported psychological distress and those who did not.

Conclusion: Socioeconomic class and orphan status were significantly associated with the HRQOL of CLHIV.

Keywords: Children living with HIV, HRQOL, PedsQL inventory, Psychologic distress.

Introduction

More Children Living with the Human Immunodeficiency Virus (CLHIV) now survive into adolescence and adulthood.^[1] This is due to the introduction of Antiretroviral Therapy (ART), which has significantly revolutionised the treatment of HIV infection, thereby increasing the life expectancy of children living with HIV (CLHIV). Hence, more children who acquired HIV via the mother-to-child route now survive into adolescence and adulthood.^[2] With this higher life expectancy, health outcomes of interest are no longer limited to survival but now include Quality of Life (QOL).^[3] Living with HIV can limit the capacity of these children and invariably affect their health-related quality of life adversely.^[4-6]

Acquiring the infection through the mother-to-child route can also mean that they may be living with an infected parent/caregiver. Living with HIV and caring for a child living with HIV may bring about some form of psychological distress in the parent/caregiver.^[7,8] Several factors are associated with the HRQOL of persons living with HIV.^[9-12] However, few studies have identified these factors in these children.

This research aimed to determine the relationship between the HRQOL of children living with HIV and the following variables: child's socio-demographic factors, orphan status, adherence to combination antiretroviral therapy, disclosure status, WHO clinical stage, presence of known current co-morbidities such as tuberculosis, and hospitalisation in the prior 12 months.

We also identified the association between psychological distress in the caregiver and caregiver's reported HRQOL of children with HIV.

Methods

Study location

The study was carried out at the paediatric HIV clinic of the Lagos University Teaching Hospital. The clinic runs every Tuesday, providing comprehensive HIV care to children exposed to or living with the virus.

Study design: It was a cross-sectional study.

Study population

The minimum calculated sample was 96. One hundred Children living with HIV and their caregivers who gave written informed consent/ assent where applicable were recruited using a stratified sampling method. Children who had been on ART for less than 8 weeks, children/caregivers who could not converse in English language and children living with HIV who had lived with their parent/caregiver for less than 12 months before the study were excluded from the study.

Recruited study participants were grouped into different categories using their age i.e. 5-7years, 8-12years, and 13-17 years. This was based on the design of the study questionnaire (PedsQL inventory). Samples were allotted to each age group based on the total number of children living with HIV in that age group, using proportionate allocation method. Ages 5-7 had a total

number of 227 children enrolled in the clinic, 567 children and 340 children for the 8-12 years and 13-17 years, respectively. Within each group, the number of allotted children was selected consecutively. This method was repeated on each clinic day until the desired sample size for every group was achieved. So, 20 children were recruited for the 5-7years group, 50 children and 30 children for the 8-12years and 13-17years groups, respectively.

Data Collection

On each clinic day, the participants were approached and the study was explained to them, thereafter, informed consent /assent was obtained from those who met the inclusion criteria. A general questionnaire was administered to all the study participants. Information obtained with the questionnaire included social demographics and medical history. This included date of birth, gender, family size, orphan status and socioeconomic class of parent/caregivers using the method proposed by Oyedeji, which uses the parent/caregiver's level of education and occupation to calculate SEC. The participants were sub-classified into upper and lower socioeconomic classes. Upper class was represented by social classes 1, 2, 3, while lower social class was represented by social classes 4 and 5. Other information included the number of hospitalisations in the prior one-year, the presence of HIV infection in other family members and adherence to ART using a 3 day recall. Being an orphan in this study referred to children who have lost at least one parent. Information on WHO clinical stage and duration on ART was obtained

from the case notes. Disclosure information was specifically asked from the parent/caregiver.

The HRQOL of the participants was determined using the PedsQL inventory version 4.0. The measurement tool was used with permission from the Mapi Research Trust, 69003, Lyon, France. The PedsQL inventory has been validated for academic use in Nigeria.^[13,14] The questionnaire was filled via an interviewer method. The PedsQL generic core scale questionnaire was administered to the parent/care giver and the child in three age categories. The three age categories include young child (5-7 years), child (8-12 years) and teen (13-17years). Each category has both child and parent reports. The questionnaire has 23 items and is robust in measuring physical functioning (8 items), social functioning (5 items), emotional functioning (5 items) and school functioning (5 items). Each item has a 3-point Likert scale of 0-2-4 for young child self-report and a 5-point Likert scale from 0 to 4 for all others. Zero represents never and 4, almost always. Each participant was questioned in the English language version of the PedsQL tool. The General Health Questionnaire (GHQ) was administered to the parents/caregivers to screen for the presence of psychological distress in caregivers. The GHQ-12 is an ideal screening device for identifying minor psychiatric disorders in the general population. It focuses on inability to carry out normal functions and appearance of new and distressing phenomena in the short term. It contains 12 items and participants were scored using the binary scoring method. A score of 3 and above was regarded as a

positive screen of distress based on cut-off score established in Nigerian studies.

Data analysis

Data obtained was inputted into Microsoft Excel 2013. Data was then imported into and analysed using IBM SPSS Statistics for Windows, Version 23.0 (Armonk, NY: IBM Corp). The information obtained from the PedsQL questionnaire was analysed according to the scoring protocol of the PedsQL. The Likert scale was reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, and 4=0.

Categorical variables such as gender and socioeconomic class were presented as absolute numbers and percentages. Continuous variables were tested for normality using the Kolmogorov-Smirnov test. Normally distributed variables such as

the composite HRQOL were represented as mean and standard deviation while skewed data such as the age at HIV diagnosis were summarised using median and interquartile range. Associations between categorical data were tested using Chi Square test. Test of significance of normally distributed variables was done using the student's t test or analysis of variance as appropriate. Statistical significance was accepted at p values < 0.05.

Results

A total number of 100 children living with HIV (CLHIV) and their caregivers were studied over a period of 6 months. The socio-demographic characteristics of the study participants are as shown in Table I.

Table I: Demographics of children studied and socioeconomic class of the caregivers

Characteristics	Children living with HIV		P value
	Yes, n=100 (%)	No, n=100 (%)	
Age groups (years)			0.987
5-7	20 (20)	20 (20)	
8-12	50 (50)	51 (51)	
13-17	30 (30)	29 (29)	
Gender			1.00
Male	50	50	
Female	50	50	
Socioeconomic class			1.00
Upper (I-III)	84%	84%	
Lower (IV-V)	16%	16%	

Age and sex did not affect the HRQOL. Children aged 5-7years had the highest mean composite HRQOL score for both child (88.42±6.88) and parent report

(89.72±10.52) while children aged 13-17 years had the lowest scores for both child and parent report, but the difference did not reach statistical significance. Socioeconomic

class significantly affected the HRQOL, as children of caregivers in the upper socioeconomic class (I-III) had higher mean composite HRQOL scores compared to those in the lower socioeconomic class (IV-V) for the parent report. Being an orphan significantly affected the HRQOL of the

children for the parent report, as the parent/caregiver reported a lower mean composite HRQOL for these children (81.79 ± 17.73 v 88.20 ± 12.68). However, for the child report, there was no difference in the mean composite HRQOL score. (Table II)

Table II: Relationship between HRQOL and demographic characteristics of the children living with HIV

Variable	Composite HRQOL score		Composite HRQOL score	
	Child report Mean score (SD)	P value	Parent report Mean score (SD)	P value
Age group, Years		0.312		0.561
5-7	88.42± 6.88		89.72± 10.52	
8-12	84.72± 14.39		85.90±15.75	
13-17	82.48± 14.83		85.62±14.80	
Gender		0.757		0.964
Male	85.20±13.41		86.52±14.87	
Female	84.36±13.58		86.65±14.29	
Socioeconomic class		0.158		0.017
Upper (I-III)	85.61±11.24		88.08±11.65	
Lower (IV-V)	80.44±21.61		78.71±23.69	
School days missed		0.545		0.627
0 (n=2)	93.44±9.28		94.38±7.95	
1-3 (n=85)	84.94±12.66		86.77±13.29	
≥4 (n=13)	82.46±18.42		84.16±21.91	

The WHO clinical stage of the CLHIV did not significantly affect the HRQOL, however, CLHIV in WHO clinical stage 1 had the highest mean composite HRQOL score while CLHIV in stage IV had the lowest mean composite HRQOL score for both child and parent report as shown in Table III. Children living in families where no other person had HIV had a higher mean composite HRQOL score compared to children in families with at least one family member with HIV for both child and parent report but the difference was not significant. The 16% of the CLHIV who were aware of their HIV status had higher mean composite HRQOL score compared with children

unaware of their status but the difference was not significant.

Only 25% of the CLHIV were hospitalized for illness in the prior 12 months and they had a lower mean composite HRQOL score compared to those who were not hospitalized for both child and parent report (Table III). Only one of the children had tuberculosis and was on treatment with anti-Koch's. The small number of patients with tuberculosis did not permit further analysis. Table IV shows the relationship between psychological distress in caregiver and composite HRQOL score of CLHIV. Psychological distress was present in 23% of caregivers of children living with HIV. The

child reported (86.72 ± 14.53 and 84.21 ± 13.13 , p value 0.464) and parent reported (87.75 ± 12.43 and 86.23 ± 15.14 , p value 0.629) mean composite HRQOL scores were

similar between children whose parents had reported psychological distress and those who did not report psychological distress.

Table III: Relationship between HRQOL and Disease-related characteristics of the children living with HIV

Characteristic	Composite HRQOL score (child report)	P value	Composite HRQOL score (parent report)	P value
WHO clinical stage of HIV		0.448		0.150
I (n=44)	86.77 ± 10.74		90.08 ± 10.30	
II (n=35)	82.26 ± 15.63		84.14 ± 16.23	
III (n=18)	84.32 ± 15.47		82.63 ± 18.87	
IV (n=3)	79.31 ± 2.81		81.67 ± 6.03	
HIV in other family members		0.052		0.538
Yes (n=87)	83.99 ± 13.80		86.31 ± 15.05	0.488
No (n=13)	90.15 ± 9.36		88.40 ± 10.54	
Child's self-awareness of HIV status		0.528		
Yes (n=16)	86.74 ± 11.82		88.91 ± 6.73	
No (n=84)	84.41 ± 13.75		86.14 ± 15.55	
HIV drug Adherence		0.345		0.515
Yes (n=92)	84.41 ± 13.73		86.86 ± 14.54	
No (n=8)	89.11 ± 8.70		83.35 ± 14.78	
Duration on ART		0.136		0.239
<5 years (n=25)	87.93 ± 11.20		89.26 ± 12.11	
>5 years (n=75)	83.74 ± 14.00		85.70 ± 15.20	
Hospitalization for illness		0.474		0.063
Yes (n=25)	82.72 ± 17.76		80.52 ± 19.84	
No (n=75)	85.48 ± 11.71		88.61 ± 11.74	

Table IV: Relationship between psychological distress in caregiver and composite HRQOL score of CLHIV

Parameter	Distressed (GHQ ≥ 3) n= 23 (%)	Not distressed (GHQ <3) n=77 (%)	p value
Child-reported composite HRQOL	$86.72(14.53)$	$84.21(13.13)$	0.464
Parent-reported composite HRQOL	$87.75(12.43)$	$86.23(15.14)$	0.629

Discussion

The age of the child did not significantly impact the child's HRQOL; however, CLHIV in the 5-7-year age group had the highest mean composite HRQOL score, while those in the 13-17-year age group scored lowest. This finding was similar to that reported by Raj *et al* who reported

higher HRQOL scores in younger children compared to older children.^[15] This is possibly due to the effect of ART, which is commenced once diagnosis of infection is made. Antiretroviral therapy reduces viral load to undetectable levels and increases CD4 count, which corresponds to an increase in immunity level and may consequently increase HRQOL. The present

treatment guideline of commencing ART once diagnosis is made, irrespective of clinical or immunologic stage, was commenced in 2015, and the younger children would have benefitted from this policy hence explaining why they are more likely to be healthy and relatively unaffected by the disease. In this study, sex did not affect the HRQOL of CLHIV. This may be due to the fact that ART is available and free for all children living with HIV. This corroborated the findings of Gupta *et al* and Aupibul.^[16,17] A large number of the study participants' caregivers were of the upper socioeconomic class (84%), and this significantly affected their HRQOL as the mean composite HRQOL score was higher in those with upper socioeconomic class compared to the lower for the parent report. This finding was similar to that reported by Gopakumaret al who found a higher HRQOL in CLHIV with increasing educational level of caregiver.^[12] Socio economic class is a function of level of education and occupation of the caregiver. Caregivers of CLHIV in the upper socioeconomic class are likely to have better decision-making capabilities, health seeking behaviour/choices, income, standard of living which can indirectly impact on their perspective on HRQOL. Being an orphan did not have any impact on the HRQOL of the CLHIV in the perspective of the children as there was no difference in the HRQOL reported by children who were orphans and those who were not. This finding is similar to report by Salako et al, who found no relationship between the HRQOL and orphan status of the children studied.^[18] However, for the parent/caregiver

report, there was a statistically significant difference in their view of the children's HRQOL as parent/caregivers of children who were orphans reported a lower HRQOL of those children. The reason for this finding is not immediately obvious, but may be related to differences between caregiver and children's perceptions.

The WHO clinical stage at the time of study did not significantly affect the HRQOL although children in WHO clinical stage I had the highest mean composite HRQOL and lowest scores were in those with stage IV disease. This finding is similar to studies of Cohen *et al* and Gopakumar *et al* that reported that clinical stage did not affect HRQOL.^[19,12] This is likely to be due to the fact that these children have been on ART since diagnosis in infancy which has been shown to reduce viral load, increase CD4 counts and overall immunity. This was not unexpected as clinical stage is an indication of severity and immunity. Disclosure did not significantly affect the HRQOL however CLHIV who were aware of their status had higher HRQOL scores compared to those unaware both for child and parent report. This finding differs from reports by Sabine *et al*, Bulaliet al and Butleret al who reported a positive correlation between disclosure and health outcomes.^[20,21] Disclosure may have led to better HRQOL scores because with disclosure, improvement is expected in adherence which in turn affects viral load(reduction), immunity (CD4 count) and consequently HRQOL. This was however not up to a level of statistical significance. The association between HRQOL and disclosure may not have been significant due to the low number

of children who had had disclosure as the low number may not be powered enough to detect a difference. Also, the low disclosure rate needs further investigation.

This study revealed prior hospitalization for illness in the previous 12 months in 25% of CLHIV. This did not significantly impact their HRQOL though a lower mean composite HRQOL score was reported for those who were hospitalized for illness for both the child and parent report. The lack of an association may be due to a sample size not powered enough to detect any difference between hospitalization in the prior 12 months and HRQOL.

In this study, the presence of psychological distress in caregiver of CLHIV did not affect the parent report of the child's HRQOL. Even though there are few studies on this variable, however Webster *et al* reported that presence of psychologic distress in caregiver was significantly associated with a lower HRQOL in the child as reported by the caregiver.^[8] This difference may have been due to the different tools used in assessing psychological distress in these parents. In this index study, the effect of frequent counselling on HIV related issues-treatment, adherence, disclosure etc. which the parents receive periodically may have led to this outcome. Also, the fact that ART is available and free for all CLHIV may have helped to relieve financial burden in caregivers such that the distress does not affect the care-givers perception of the child's HRQOL. The presence or absence of psychological distress in caregiver of a child living with HIV is important as it may impact on the ability of such caregiver to positively care for the child.^[22] This means

that parent report on HRQOL of CLHIV may be relied upon irrespective of psychological distress in parent.

Limitations: Exclusion of participants/caregivers who are unable to converse in English language due to non - availability of validated local dialect translations of the PedsQL inventory may limit the generalizability of the findings of this study.

Conclusion

Socioeconomic class of parents/caregivers and orphan status of CLHIV significantly affects the HRQOL of CLHIV. Hence interventions geared towards improvement of socioeconomic class may improve the HRQOL of CLHIV.

Ethical considerations: Approval for the study was obtained from the Human Research and Ethics Committee of LUTH before commencement of the study. (ADM/DCST/HREC/APP/2632) Written informed consent was also obtained from the parents or caregivers and assent from children greater than 7 years. Participation in the study was voluntary and free. Confidentiality of all participants was maintained, and participants were given the freedom to withdraw from the study at any time.

Acknowledgements: The authors are grateful to the children and parents/caregivers who participated in this study.

Author's contributions: AEA, AMA and ECI conceived the study. AEA and ECI wrote the literature review. AEA, AMA, OEE drafted the manuscript. All the authors revised the manuscript draft for intellectual content and approved the final version of the manuscript.

Conflict of interest: All the authors have no conflict of interest to disclose.

Source of Funding: No funding was received for this research.

Publication history: Submitted 11 September 2025, Accepted 14 February 2026

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