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Original Research Article

Health-related quality of life of HIV-infected children in Uyo. Akwa Ibom State, Nigeria

Fadekemi Folasade Megbelayin*, Mkpouto Udeme Akpan, Ofonime Dixon-Umo

Department of Paediatrics, University of Uyo Teaching Hospital, Uyo. Akwa Ibom State, Nigeria

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***Correspondence:**
Dr. Fadekemi Folasade Megbelayin,
E-mail: kemifav@gmail.com

ABSTRACT

Background: HIV-infected children are surviving into adolescence and adulthood due to the effectiveness of highly active antiretroviral therapy (HAART) but they now have to cope with living with a chronic disease. Health-related quality of life (HRQOL) has been shown to be an invaluable tool in assessing health outcome in chronic health conditions including HIV. Little is known about the HRQOL of HIV-infected children in both developing and developed countries. The study aimed at assessing the HRQOL of Nigerian children with HIV infection and compare it with that of healthy children in Uyo.
Methods: A cross-sectional study of 211 HIV-infected children aged 2 to 15 years and 211 age, sex and social class-matched HIV-uninfected children with their caregivers was conducted at the University of Uyo Teaching Hospital, Uyo for a duration of nine months from October 2016 to July 2017. A generic version of the Pediatric Quality of Life Inventory (PedsQL 4.0) was used to measure their HRQOL.
Results: From both self and proxy reports, there was no significant difference in the mean total HRQOL score of HIV-infected children and that of HIV-uninfected children.
Conclusions: HRQOL of HIV-infected children in Uyo, Akwa Ibom state was good and comparable to that of HIV-uninfected children. Assessment of HRQOL should be incorporated into routine antiretroviral therapy ART programmes as a measure of the outcome of disease management. This will further help to identify needs and direct interventions for holistic care of these vulnerable children.

Keywords: Health-related quality of life, Paediatric HIV, PedsQL, Proxy report, Self- report

INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) caused by Human Immunodeficiency Virus (HIV) infection is a global pandemic.[1] Nigeria has the highest burden of Paediatric HIV/AIDS in Sub-Saharan Africa with over 380,000 children between the ages of 0 and 14 years living with HIV.[2]

The advent of highly active antiretroviral therapy (HAART) in 1996 with the use of combination antiretroviral therapies, prophylaxis treatment for opportunistic infections and other supportive medications have helped to improve the life expectancy of People Living with HIV/AIDS (PLWHA).[3-7] Infected persons now live longer due to the effectiveness of HAART in suppressing viral load and reducing HIV-related morbidity and mortality.[7] Many HIV-infected children are surviving into adolescence and adulthood but they now have to cope with living with a chronic disease.[7-9] Chronic diseases often affect the quality of life.[9] The World Health Organization (WHO) defines Quality of

life as "an individual's perceptions of his/her position in life in the context of the culture and value system in which he/she lives and to his/her goals, expectations, standards and concern''.[10-11]

Health-related quality of life (HRQOL) is defined as the patient's appraisal of how his/her well-being and level of functioning, compared to the perceived ideal, are affected by individual health.[10,12-13] Health-related quality of life (HRQOL) has been widely applied in evaluating the effects of treatment on different populations.[13-18]

HRQOL has become an important measurable outcome of treatment in the era of highly active antiretroviral therapy HAART, rather than the traditional outcomes of mortality, estimates of the frequency and severity of diseases, survival rates, the occurrence of opportunistic infections, CD4 count and viral load.[15-18]

Studies have shown that the presence of HIV/AIDS, as well as the symptoms and complications associated with HIV/AIDS, have negative effects on the quality of life of people living with HIV/AIDS including children.[14-20] Banerjee et al in a hospital-based study done among 100 HIV-infected children compared with 200 uninfected children in New Delhi in 2008, found that HIV infection was associated with a negative impact on quality of life among children with lower scores for physical, school, and emotional functioning and health symptoms compared to healthy controls.[18]

Several studies have been done within and outside Africa, Nigeria inclusive, on the health-related quality of life among HIV-infected patients especially adults.[14,18-20] There is however paucity of literature on the health-related quality of life of HIV-infected children in Nigeria despite having the high burden of paediatric HIV. Accurately assessing HRQOL in HIV-infected patients is necessary, as it may affect disease management, including therapy and additional counselling, future preventive behaviours, prognosis, social services, special needs in education and to maximize the children's potential as they move into adolescence and adulthood.[14,17-21]

There are no studies or publications on the health-related quality of life of HIV-infected children in Uyo, Akwa Ibom state to the best of the author's knowledge.

This study aimed at determining the health-related quality of life of HIV-infected children in Uyo, Akwa Ibom state.

METHODS

This hospital-based comparative cross-sectional study was carried out in the Paediatric Infectious Diseases Clinic and Children Outpatient Clinic of the University of Uyo Teaching Hospital (U.U.T.H), Uyo in Akwa Ibom state for nine months from October 26th 2016 to July 26th 2017. The Paediatric Infectious Diseases Clinic is a specialist clinic which runs on Wednesdays. Statistics from the clinic register showed average monthly clinic attendance of 70. The children are often seen on 2-3 monthly visits. U.U.T.H is the only tertiary health facility in Akwa Ibom state and it provides health care to residents from both within and outside the state. Ethical clearance was obtained from the Ethics Committee of the University of Uyo Teaching Hospital (UUTH), Uyo. Informed consent was obtained from the parents and assent from the older children from 7 years. Before the commencement of the study, permission to use PedsQL was obtained from the copyright owner (Mapi Research Trust, Lyon, France). The subject group was 211 HIV-infected children aged 2-15 years, at least 3 months since diagnosis recruited consecutively.

Controls were apparently healthy, HIV-negative children, matched for age and gender and socioeconomic status and had no chronic illness. They were selected from children attending the child welfare clinic for growth monitoring, those who presented to the out-patient clinic for follow-up visits, laboratory results review for non-chronic ailments such as malaria, upper respiratory tract infection and school entry medical examination.

Children with other chronic illnesses such as asthma, cerebral palsy, epilepsy, nephrotic syndrome and sickle cell anaemia were excluded from the study.

Sample size estimation

The sample size for this study was determined using a proportion of 50% since there was no available local data. The minimum sample size was calculated

$n= 2z^2pq/ d^2$

where, n= minimum sample size, z=the normal deviate set at 1.96 corresponding to the 95percent confidence level, p=Proportion used was 50%, d= the minimum expected difference between the two means set at 0.1, n= 192 with a projected non-response of 10%, a minimum sample size of 211 was used.

A pro forma was filled out containing the participant's biodata, father /mother's educational status, father/mother's occupation, living status of the parents, disclosure status, time of diagnosis, HAART use and latest CD4 count. Social class was determined using the Oyedeji classification.[22] The score for the parents' (or guardians') occupational status plus those of their educational levels were added together and the mean of the total of these four scores to the nearest whole number was regarded as the child's social status score. Social class 1 and 2 are high, 3 are middle class while 4 and 5 are low.

Pediatric quality of life inventory (PedsQL4.0) Generic code is a standardized instrument for the assessment of HRQOL of HIV-infected children.[18,20] It has two

components: the child's report (>5 years) and the parent's proxy report (2-18 years).[18-20]

Generic code assesses health-related quality of life in 4 domains: Physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items). Each of the 23 items states a problem; for example, "difficulty walking". Parent proxy reports are a parallel version of the child self-reports. Differences are the use of age-appropriate language and first- or third-person tense. The PedsQL refers to two different periods: the past month or the past week. The past month's version was used in this study to assess for chronicity.

The pre-tested questionnaire was interviewer-administered and each eligible child and primary caregiver was administered the questionnaire separately. PedsQL was administered to the participants in English.

The parent or child indicated on a 5-point Likert scale to what extent the child had difficulties with that problem. Answering options included never (0), almost never (1), sometimes (2), often (3) and almost always (4)

Interpretation of score: Each answer was reversed scored and re-scaled to 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0). Overall scores and sub-scale scores were computed as the sum of the scores on the items divided by the number of items answered, Total Score was the sum of all the items over the number of items answered on all the scales. The psychosocial score was the sum of all the items in emotional, social and school functioning over the number of items answered on the 3 scales. High score signified good quality of life. The established cut-off scores meaning the poor quality of life by using the PedsQL generic instrument were 69.7 for the child self-report and 65.4 for the parental proxy report in comparison with the general population.

Data analysis

Crude data was coded, entered and analyzed using Statistical Package for Social Sciences (SPSS 20.0 Polar Engineering and Consulting, USA). The mean score of Health-Related Quality of Life for each domain was determined. Differences in mean scores were compared using the Student's t-test. The p-value less than 0.05 was considered significant.

RESULTS

Most of the subjects/controls (48%) were between the age of 8 and 12 years. The male: female ratio was 1.2:1. Majority belonged to the middle socioeconomic class as shown in Table 1.

The study also included the parents/caregivers of HIV-infected and uninfected children. The majority of the caregivers' 81% in the HIV-infected group and 80% in the uninfected group were females. Biological parents constituted 78.2 % of the HIV-infected group and 96.2% in the comparison group.

Table 1: Social-demographic characteristics of the study population.

Variable	N (%)
Age of children (Years)	
2-4	35 (16.6)
5-7	46 (21.8)
8-12	102 (48.3)
13-15	28 (13.3)
Sex	
Male	117 (55.5)
Female	94 (44.5)
Social class	
High	77 (36.5)
Middle	83 (39.3)
Low	51 (24.2)

Table 2: Socio-demographic characteristics of parents/caregivers.

Variable	HIV-infected N= 211 N (%)	HIV-uninfected N= 211 N (%)	Chi-square (p value)
Age of caregivers (years)			
≤25	16 (7.6)	7 (3.3)	
26-36	86 (40.8)	102 (48.3)	19.02 (0.002
37-47	69 (32.7)	87 (41.2)	
48-58	25 (11.8)	10 (4.8)	
59-69	11 (5.2)	5 (2.4)	
>69	4 (1.9)	0 (0)	
Sex			
Male	117 (55.5)	42 (19.9)	0.02 (0.90)
Female	94 (44.5)	169 (80.1)	
Relationship with the child			
Biological parent	165 (78.2)	203 (96.2)	29.49 (0.0002)
Grandparents	12 (5.7)	4 (1.9)	
Relatives	28 (13.3)	4 (1.9)	
Others	6 (2.8)	-	

All the HIV-infected children were on highly active retroviral drugs (HAART). 92 out of the 211 HIV-infected children were between one and five years since diagnosis. Only 32 (out of these HIV -infected were aware of their HIV diagnosis.

The self–report (Table 4) showed that the mean total score of HRQOL of HIV-infected children was not significantly different from that of uninfected children; p= 0.49. Among the specific domains, the mean scores for physical and emotional were significantly higher in HIV-infected children compared to uninfected children (p=0.04 and 0.006) respectively. HIV-infected children

had a significantly lower mean score in school functioning compared to uninfected children; p=0.02).

Table 3: Clinical characteristics of HIV-infected children.

HAART use	N (%)
Yes	211 (100)
No	0
Disclosure	
Yes	32 (15.2)
No	179 (84.8)
Time since diagnosis <1 year	24 (11.4)
1-5	92 (43.6)
6-10	89 (42.2)
>10	6 (2.8)
Clinical stage	
1	28 (13.3)
2	92 (43.6)
3	73 (34.6)
4	18 (8.6)

Table 4: Mean self-reported HRQOL score of children with HIV and control.

Domains	HIV-infected Mean±SD N=176	Non-HIV infected Mean±SD, N=176	P value
Physical	96.72±6.94	95.24±6.36	0.04
Emotional	91.73±12.11	87.72±15.07	0.006
Social	97.78±6.29	98.01±5.86	0.73
School	86.11±13.16	89.35±12.30	0.02
Psychosocial	91.88±7.95	91.69±8.55	0.84
Total	93.11±6.98	92.58±7.57	0.49

Table 5: Mean parent proxy HRQOL score of children with HIV and control.

Domains	Parents HIV-infected children N=211 mean±SD	Parents HIV-uninfected children N=211, mean±SD	P value
Total	93.88±6.59	92.58±7.14	0.053
Physical	97.55±5.23	95.55±7.17	0.001
Emotional	91.35±11.84	87.44±13.78	0.002
Social	98.84±6.59	97.91±6.17	0.14
School	87.46±12.62	89.22±11.78	0.15
Psychosocial	92.53±8.01	91.51±8.29	0.20

There was no difference in psychosocial functioning between HIV-infected and uninfected children (p=0.84)

The parent proxy report (Table 5) showed that the mean HRQOL of HIV-infected children was not significantly different from that of uninfected children; p= 0.053. Among the specific domains, the mean scores for physical and emotional functioning were significantly higher in HIV-infected children compared to uninfected children (p=0.001 and 0.002).

However, there were no significant differences between the mean scores for psychosocial, social and school domains in HIV-infected children and uninfected children.

DISCUSSION

The most relevant finding in this study was the overall good health-related quality of life (HRQOL) of HIV-infected children in Uyo, Akwa Ibom state-as measured with a generic instrument, the PedsQL.

They had high scores on both self and proxy reports, which connote good health-related quality of life. This may be because all the HIV-infected children were on antiretroviral drugs as stipulated by 2015 national guidelines. ART has been reported to be effective in improving the HRQOL by improving the immune status of the patients.[5,18,28] Baneerjee et al in India and Kuntawee et al in Thailand reported that antiretroviral treatment may be associated with improved quality of life among HIV-infected children.[8,5] Better quality of life is an important indicator of treatment efficacy.

This finding of overall good health-related quality of life of HIV-infected children was like findings of several authors who assessed similar patient populations from both developed and developing countries.[9,10,17,21,3,4,23,24]

The highest mean score of the HIV-infected children was in social functioning followed by physical functioning. This pattern was the same for both self and proxy reports. Some authors in developed countries also reported this.[10,14] It was reported that HIV-infected children had better access to health services and social support which could have affected their perceived HRQOL. However, Diniz et al in Brazil had the lowest score in social functioning and it was due to stigma and physical limitations associated with HIV.[17]

HIV-infected children had the lowest mean score in the school functioning domain from both self and proxy reports. This finding is consistent with the previous studies.[24,25] This contrasted with what Auripul et al found in Thailand.[10] Low school functioning may be due to missing school to attend clinics for checkups and past illnesses/opportunistic infections which may have affected learning capabilities. Prior studies on HIV-infected children found that HIV-infected children performed poorer on several domains including intelligence and information processing.[25,26] This finding of a lower mean score in school functioning implies there is a need for more research to find out the reasons in Uyo.

There was no difference between the mean total score of the HIV-infected children and uninfected children on

both self and proxy reports. This finding is like what was reported by Aurpibul et al in Thailand.[10] This finding is at variance with previous studies which showed that HIV-infected children have lower scores when compared with healthy children.[8,12,13,27] This lower score in these comparative studies may be due to differences in sample sizes and ages of subjects. The present study recruited participants from 2 years to 15 years of age and had a larger sample size, while other comparative studies had smaller sample sizes and recruited mainly adolescents.

This study found that physical and emotional functioning was significantly better in HIV-infected children than in uninfected children on both self and proxy reports. This could be because these HIV-infected children had been in antiretroviral care for some months and had received psychological support compared to the control group.

This study has some limitations. It was a cross-sectional analysis of HIV-infected and uninfected children with just one HRQoL assessment. PedsQL is a generic questionnaire and not a disease-targeted questionnaire.

CONCLUSION

This study found high mean HRQOL scores for HIV-infected children on both self and proxy reports; hence, the overall HRQOL of HIV-infected children in Uyo were good. HRQOL should be assessed as a routine and in the subsequent follow-up of HIV-infected children as a measure of the outcome of disease management. Such assessment of HRQOL will enhance the early identification of problems and prompt implementation of intervention strategies.

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