ORIGINAL ARTICLE

Caregivers' perception of oral health-related quality of life in a group of Nigerian children living with human immunodeficiency virus

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Abstract

Aim: This study examined the caregivers' perception of the effect of dental conditions on general well-being and family life of a group of human immunodeficiency virus (HIV)-infected Nigerian children. A secondary aim was to investigate correlations between the children's sociodemographic and health-related variables and caregivers' global ratings of oral health and well-being.

Study Design A cross-sectional questionnaire-based survey was conducted among parents/caregivers of 95 HIV-positive children receiving care at the Lagos State University Teaching Hospital, Nigeria.

Materials and Methods: The "Parental-Caregivers Perception Questionnaire" which included measures of global ratings of oral health and well-being as well as effects of oral health on domains of oral symptoms, functional limitations, emotional well-being, and family well-being/parental distress was used. Assessment was based on the child's oral health within the preceding 3 months of the study.

Results: The most affected subscale of the oral health-related quality of life was functional limitation followed by parental distress and then oral symptoms. Caregivers of older children were 2½ times more likely to view oral health as impacting their child's overall health (P = 0.034). Furthermore, caregivers of children who had not yet commenced antiretroviral therapy were 15% more likely to report oral symptoms (P = 0.024) and 11% were more likely to be distressed.

Statistics: Data entry, validation, and analysis were done using SPSS version 17.0. Findings were considered to be statistically significant when 95% confidence intervals were not overlapping.

Conclusions: According to caregivers' perceptions, oral symptoms, functional limitations, and parental distress outweighed emotional well-being in impacting a child's oral health quality of life. Oral health programs to improve the knowledge of caregivers on the importance of oral health in HIV-positive children are necessary for improvement in overall quality of life.

Key words: Caregivers, human immunodeficiency virus infection, Nigerian children, oral health-related quality of life

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Introduction

According to Petersen,[1] oral health cannot be separated from general health because it is an important component of an individual's quality of life. Oral health-related quality of life (OHRQOL) refers to the impact oral health or disease has on an individual's daily functions.[2] These measures can be used as clinical indicators when assessing the oral health of individuals, making clinical decisions, and evaluating dental interventions, services, and programs. They are also helpful when assessing outcomes of oral disorders because

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they are multi-dimensional, considering symptoms, physical functioning, emotional, and social well-being.[3]

Research suggests that oral diseases could result in pain, suffering, psychological disorders, and social problems which could lead to individual and societal loss.[4] In children, oral diseases could cause impaired chewing, reduced appetite, sleep problems, weight loss, behavioral changes, and poor school performance.[5,6] In addition, poor oral health in children may affect family welfare because parents/caregivers feel guilty for their children's problems, lose valuable working hours, and face the high cost of dental treatment.[5]

Individuals living with the human immunodeficiency virus (HIV) infection commonly present with oral lesions such as oral candidiasis, gingivitis, periodontal disease, and dental caries, and these lesions are sometimes seen in the early stages of the infection.[7-9] Oral conditions in such persons are considered useful markers of disease progression and immunosuppression.[9] Therefore, families with HIV-positive children are frequently faced with a double burden; one from the oral disorders and the other from the HIV infection. Consequently, they tend to experience emotional and financial strain while trying to access all the needed health services (including oral health services) for their children. This is important in developing countries like Nigeria that are often resource poor and have limited access to healthcare, particularly oral healthcare.

Research findings confirm that oral health has an impact on OHRQOL among HIV-positive children.[10] Several tools have been developed to measure various aspects of OHRQOL in children. One such tool, the Parental-Caregiver Perceptions Questionnaire (P-CPQ) was developed and validated by Jokovic *et al*.[11] to measure parental/caregiver perceptions of a child's OHRQOL and the impact of the child's oral and orofacial conditions on the family. This is based on the view that parents/caregivers are often the main decision makers regarding a child's health and their perceptions have a major influence on treatment choices.[12-15] Little research has been done as to the characteristics and OHRQOL among HIV-positive children in Nigeria who often have unmet dental care needs.[16] It is important to measure the impact of dental disease in these children on their caregivers and families as part of assessing OHRQOL in children living with HIV/AIDS.

An understanding of the perception of their parents/caregivers may be useful for developing an oral health promotion program that will focus on addressing the high unmet oral health needs in this population. It is also essential for dental practitioners to have some appreciation for how the oral health conditions of these children affect their general well-being, quality of life, and family life in order to provide the needed dental treatment in a meaningful and compassionate manner. Thus, this survey was designed to assess the perception of parents and caregivers regarding the impact of oral health conditions on general well-being and family life of children living with HIV/AIDS receiving care in Lagos State University Teaching Hospital (LASUTH) pediatric clinic. A secondary aim of the study was to investigate correlations between sociodemographic and health-related variables of these children and their global ratings of oral health and well-being.

Materials and Methods

The minimum sample size computed using the national prevalence of HIV in children (4.5%) was 73 children. All consecutive children receiving care in the pediatric outpatient Unit of LASUTH during the study period were recruited into

Table 1: Sociodemographic, behavioral, and clinical variables of respondents and caregiver's global rating of child's oral health

Variable	*n* (%)
Sociodemographic variables	
Age category (years)	
5-10	80 (84.2)
11-14	15 (15.8)
Gender	
Male	53 (44.2)
Female	42 (55.8)
Caregiver	
Father	13 (13.7)
Mother	64 (67.4)
Relative	16 (16.8)
Other	2 (2.1)
Health related behaviors	
Frequency of tooth brushing	
<2 times daily	80 (84.2)
Two or more times daily	15 (15.8)
Clinical variables	
Treatment status	
Commenced ARV	80 (84.2)
Not on ARV	15 (15.8)
Caregivers rating of child's oral health status	
How would you rate your child's oral health?	
Excellent	10 (10.5)
Very good	21 (22.1)
Good	29 (30.5)
Fair	16 (16.9)
Poor	19 (20.0)
How much is your child's overall well-being affected by the condition of the mouth?	
Not at all	43 (45.3)
Very little	11 (11.6)
Some	8 (8.4)
A lot	20 (21.0)
Very much	9 (9.5)
I don't know	4 (4.2)
Total	95 (100.0)

ARV=Antiretroviral therapy

the study after obtaining informed consent from the parent or caregiver. All children who participated in this study were infected with HIV through vertical transmission. Exclusion criteria comprised refusal of child or caregiver to participate and failing to attend scheduled hospital consultations in the period of data gathering. Ethical approval was also obtained from the Ethics and Research Committee of LASUTH.

The survey instrument used for recording details comprised two sections. The first section obtained information on sociodemographic, behavioral, and medical variables, while the second section contained questions from the P-CPQ. The sociodemographic variables considered were age, sex, caregiver (i.e., mother, father, or other person). Information regarding the clinical status was obtained from the medical records of the patient, while the caregiver provided information on toothbrushing frequency (classified into 2 more times daily or less than twice daily).

The 26-item P-CPQ oral health quality-of-life questionnaire was administered to the child's parents/caregiver by a trained interviewer. Overall OHRQOL was assessed on a 5-point response scale by the following two questions: "How would you rate the health of your child's teeth, lips, jaws, and mouth?" (excellent = 5 to poor = 1) and "How much is your child's overall well-being affected by the condition of his/her teeth, lips, jaws, or mouth?" (Not at all = 1 to very much = 5). The P-CPQ tested four domains to ascertain oral health quality of life: Oral symptoms (7 items), functional limitations (7 items), emotional well-being (3 items), and family well-being/parental distress (7 items). Items within each subscale asked about the frequency of various tooth-related events "in the past 3 months." Each question was answered by selecting one of five alternative responses. These alternatives were assigned values of 0–4, with the higher values corresponding to a poorer QOL.

The data were cleaned then analyzed using the SPSS for Windows (version 17.0; SPSS Inc. Chicago, IL, USA) statistical software package. Descriptive statistics was used to summarize the responses to the survey questions. Average scores from the questions listed under each domain were computed as well as the overall QOL score. A multivariate analysis of variance was used to identify the major relationships between the overall oral health and well-being questions and the possible predictor variables: Gender, age, condition, and the four domain scores. Differences in mean scores were analyzed using the Student's *t*-test or analysis of variance test as appropriate. Correlation analysis was done to estimate the relationship between P-CPQ domains and sociodemographic characteristics. A multiple regression analysis was then used to describe the significant predictors of overall oral health and well-being. A 95% confidence interval and 5% level of significance was adopted.

Results

Sociodemographic and clinical features of study population

A total of 95 caregivers of HIV-positive children participated in this survey. The children's ages were between 5 and 14 years

Table 2: Relationship between parental perception of overall health of child's mouth, well-being, and P-CPQ domains

	Number	Mean scores				
		Oral symptoms	Functional limitation	Emotional well-being	Parental distress and family function	Overall P-CPQ score
Health of child's mouth						
Excellent	10	1.600	0.700	2.200	5.700	17.700
Very good	21	1.905	1.429	0.810	5.429	16.143
Good	29	2.069	2.586	1.483	7.138	18.172
Fair	16	2.375	2.125	1.625	5.625	15.938
Poor	19	5.211	4.947	3.158	10.790	27.684
Total	95	2.579	2.547	1.768	7.053	19.200
P		0.050	0.006*	0.079	0.001*	0.002*
F		2.478	3.874	2.168	5.040	4.577
Well-being affected by the mouth						
Don't know	4	1.250	4.750	0.500	9.000	18.250
Not at all	43	1.744	1.721	1.581	6.581	15.651
Very little	11	3.000	2.546	2.546	5.909	18.909
Some	8	3.750	2.625	1.625	7.000	20.250
A lot	20	3.450	3.400	1.800	7.700	23.100
Very much	9	4.556	3.333	2.333	8.778	27.333
Total	95	2.579	2.547	1.768	7.053	19.200
P		0.323	0.362	0.799	0.644	0.389
F		1.186	1.108	0.468	0.675	1.059

*Significant. P-CPQ=Parental-Caregiver Perceptions Questionnaire

Table 3: Summary of overall indices on oral health and main domain scores

Domains	Mean score (SD)	Correlations			
		Oral symptoms (*P*)	Functional limitation (*P*)	Emotional wellbeing (*P*)	Parental distress (*P*)
"How would you rate your child's oral health?"	2.863 (1.268)	−0.242 (0.018)*	−0.379 (0.000)*	−0.158 (0.125)	−0.308 (0.002)*
"How much does the condition of your teeth, lips, jaws, or mouth affect your life overall?"	2.295 (1.487)	0.152 (0.142)	0.132 (0.203)	0.028 (0.785)	0.127 (0.221)
Oral symptoms	2.66 (4.12)	-	-	-	-
Functional limitation	2.53 (3.540)	0.276 (0.007)*	-	-	-
Emotional well-being	1.77 (2.71)	0.160 (0.123)	0.213 (0.038)*	-	-
Parental distress	7.08 (4.65)	0.263 (0.010)*	0.331 (0.001)*	0.225 (0.028)*	-
Overall score	19.20 (10.61)	0.561 (0.000)*	0.655 (0.000)*	0.495 (0.000)*	0.779 (0.000)*

*Significant. SD=Standard deviation

Table 4: Factors associated with overall indices on parental perception of oral health, well-being, and total CPQ scores

	Perception of oral health mean	RR (95% CI) significance	Perception of overall well-being mean	RR (95% CI) significance	Overall C-PCQ score mean	RR (95% CI) significance
Sociodemographic characteristics						
Gender						
Male	2.929	0.917 (0.397-2.125)	2.024	1.641 (0.690-3.903)	17.548	1.060 (0.992-1.1320)
Female	2.811		2.509		20.509	
P		1.000		0.286		0.252
Age category (years)						
5-10	2.886	0.446 (0.146-1.360)	2.275	1.817 (0.595-5.553)	18.650	12.154 (1.027-143.846)
11-14	2.733		2.400		22.133	
P		P=0.159		0.377		0.064
Caregiver						
Mother	3.016	2.063 (0.855-4.976)	2.422	2.346 (0.882-6.242)	19.516	0.908 (0.084-11.100)
Other	2.548		2.032		18.548	
P		0.118		0.109		1.000
Health related behavior						
Frequency of brushing						
<2 times daily	2.888	0.853 (0.276-2.638)	2.313	0.417 (0.109-1.597)	19.125	0.963 (0.922-1.005)
Two or more times daily	2.733		2.200		19.600	
P		0.778		0.246		1.000
Clinical variable						
Treatment status						
Commenced ARV	3.062	4.400 (1.362-14.219)	2.288	1.077 (0.335-3.462)	17.288	0.359 (0.030-4.231)
Not on ARV	1.800		2.333		29.400	
P		0.017*		1.000		0.406

*Significant. C-PCQ=Children-Parental Caregiver Questionnaire; CI=Confidence interval; RR=Relative risk; ARV=Antiretroviral therapy; CPQ=Caregiver Perceptions Questionnaire

with mean age of 7.8 years (standard deviation = 3.49). A large proportion of the caregivers (67.4%) were mothers. Most of the children (84.2%) had commenced antiretroviral therapy prior to the survey. Table 1 reports the sociodemographic, oral health behavior, and clinical features of the study population.

Parental perception of child's oral health and well-being

More than half of the respondents (63.2%) rated their wards' oral health as excellent, very good or good. Conversely, only 39.0% of the study participants considered oral health as an important component of their wards' overall health [Table 1].

Relationship between overall health of child's mouth and Parental-Caregiver Perceptions Questionnaire domains

The subscales of oral symptoms, functional limitation, and family well-being/parental distress were significantly correlated ($P < 0.05$) to the item assessing the caregiver's perception of their child's overall oral health [Table 2]. Parents/caregivers reporting poor overall oral health of their children's mouth reported more oral symptoms, more functional limitations, higher parental stress, and impact on family function. The caregivers considered the domain of functional limitation as the most affected by oral diseases

Table 5: Factors associated with the P-CPQ subscales

	Oral symptoms	RR (95% CI) significance	Functional limitations	RR (95% CI) significance	Emotional well-being	RR (95% CI) significance	Parental distress	RR (95% CI) significance
Sociodemographic characteristics								
Gender								
Male	2.333	1.039 (0.985-1.096)	1.929	1.104 (1.012-1.204)	1.691	3.347 (0.360-31.133)	6.643	1.061 (0.224-5.025)
Female	2.925		3.000		1.830		7.434	
P		0.501		0.064		0.379		1.000
Age category (years)								
5-10	3.024	0.975 (0.940-1.010)	2.762	3.949 (0.601-25.962)	1.643	3.949 (0.601-25.962)	7.452	1.039 (0.985-1.096)
11-14	3.539		3.154		2.077		7.000	
P		1.00		0.176		0.176		0.305
Caregiver								
Mother	2.313	0.476 (0.028-7.876)	2.422	0.713 (0.113-4.504)	1.531	0.301 (0.048-1.903)	7.813	0.622 (0.130-2.969)
Other	3.387		2.742		2.258		5.581	
P		0.548		0.660		0.326		0.679
Health related behavior								
Frequency of brushing								
<2 times daily	2.425	5.643 (0.333-95.571)	2.563	0.938 (0.886-0.992)	1.738	0.938 (0.886-0.992)	7.200	0.9133 (0.853-0.977)
Two or more times daily	3.933		2.333		1.933		6.467	
P		0.292		1.000		1.000		0.592
Clinical variable								
Treatment status								
Commenced ARV	1.950	0.867 (0.711-1.057)	2.100	0.253 (0.039-1.665)	1.338	0.253 (0.039-1.665)	6.550	0.107 (0.021-0.544)
Not on ARV	6.467		4.800		4.067		9.933	
P		0.024*		0.176		0.176		0.011*

*Significant. CI=Confidence interval; RR=Relative risk; ARV=Antiretroviral therapy; P-CPQ=Parental-Caregiver Perceptions Questionnaire

followed by parental distress and then oral symptoms. Children whose caregivers scored their oral health status as excellent were observed to have significantly better scores in these domains and in the overall Children-Parental Caregiver Questionnaire (C-PCQ) scores. Although parents reporting poor overall oral health for their children also reported reduced emotional well-being the relationship was not statistically significant.

Relationship between child's overall well-being and Parental-Caregiver Perceptions Questionnaire domains

Table 3 shows the relationship between the caregiver's assessment of their wards' oral health, overall well-being, and the scores on the C-PCQ. Children whose parents/caregivers described their overall well-being as being affected by their mouth reported more oral symptoms, more functional limitations, more emotional disturbance, higher parental stress, and greater impact on family function [Tables 2 and 3]. The overall C-PCQ score for such caregivers was higher than those of parents reporting less impact on overall well-being. These relationships were, however, not statistically significant ($P > 0.05$).

Factors associated with subscales and overall scores on the Children-Caregiver Perceptions Questionnaire

Caregivers whose children had not yet commenced antiretroviral therapy were 4 times more likely to report poor oral health status ($P = 0.015$). Furthermore, caregivers of children who had not yet commenced antiretroviral therapy were 15% more likely to report oral symptoms ($P = 0.024$) and their parents/caregivers were 11% more likely to be distressed [Tables 4 and 5]. Stepwise multiple regressions indicated the child being irritable as the only significant predictor of overall oral health ($P = 0.000$). While the factors most likely to predict effects of oral health on overall well-being were longer eating, difficulty eating, difficulty eating cold foods, and parents having less time for themselves or the family ($P = 0.000$).

Discussion

Research reports have confirmed the importance of oral health among children living with HIV,[10,17] because of the higher occurrence of dental lesions in this population.[18] However, little is known about the perception of parents/

caregivers of HIV-infected children toward oral health. Our study is the first to assess parents/caregivers' perceptions of the functional, emotional, and social consequences of the poor oral health of children living with HIV in Nigeria and sub-Saharan Africa. Assessment of such indices of oral health as it relates to well-being among children with HIV is important. First, it serves, as a basis to highlight the perceived oral health promotion needs in this population. Second, it paves the way for the development of oral health programs that would target and address these needs. Third, it highlights the baseline to monitor and improve the oral health and overall well-being of these children.

Our first main finding was that the subscales of daily function and parental distress were the most affected by oral health. This differs from the result of a similar study conducted among Brazilian children living with AIDS, where the presence of oral symptoms was the most affected subscale.[17] The difference in the results is attributable to the fact that the respondents in the present study were parents/caregivers while those in the Brazilian study were the affected children. In addition, the Brazilian children had developed full-blown AIDS, which is associated with more severe oral symptoms. Regarding parental distress, many respondents reported feelings of "guilt" which probably explains the correlation of the P-CPQ scores and their assessment of their child's oral health. The fact that all the children in this study were infected by vertical transmission is the most likely reason for this correlation. Counseling of caregivers of HIV-positive children to deal with feelings of guilt is suggested in order to ensure good quality of life for both the caregiver and their wards.

Our second main finding was that approximately four out of ten parents/caregivers stated that oral health affected the overall well-being of their children with HIV. Thus, a higher proportion of parents/caregivers did not recognize the impact of poor oral health status on the emotional well-being of children with HIV. However, the relationship between the caregivers assessment of the impact of well-being on oral health was not statistically related to the ratings of the P-CPQ subscales. Obviously, this belief could be a barrier to seeking oral health care as many of the children surveyed had never visited a dentist prior to the study. There is a need to address this misconception by developing appropriate oral health promotion programs to motivate good oral health seeking behavior among parents/caregivers of children living with HIV.

The third main finding was that parents and caregivers rated the oral health of their child fairly high. This was probably because many of the children had commenced antiretroviral therapy and thus had few dental complaints in the 3 months preceding the survey. When compared with scores on the P-CPQ it was observed that the subscales of oral symptoms, functional limitation, and parental distress were significantly correlated with the caregivers' assessment of the child's oral health. A similar result was obtained by Baens-Ferrer *et al*.[19] in a study assessing parental perceptions of OHRQOL among children with special health needs. Clearly, the caregivers surveyed do not consider the child's emotional well-being as an important indicator of oral health status. This may be because caregivers are more likely to note obvious oral symptoms and functional limitations than perceive the child's emotional state. The pressures and demands of caring for these children may also hamper the ability recognize emotional problems. There is a need to educate caregivers of children living with HIV on the value of emotional state to oral and general health.

In identifying factors related to the P-CPQ score, more parents of older children felt oral health had an impact on overall well-being. This view could be attributed to the fact that parents with older children would have gained experience from caring for these children over the years than parents of younger children. Furthermore, the commencement of antiretroviral therapy was observed to be associated with fewer oral symptoms and less parental distress. This shows the value of early diagnosis and timely treatment in the management of HIV-positive children.

One apparent limitation of this study is that parents/caregivers acted as "proxy raters" for their child. Concerns have been raised about the accuracy of using parental assessments as a measure of OHRQOL.[20,21] Researchers have suggested that the views of both parent and children should be obtained in order to fully represent the child's OHRQOL.[22,23] However, Parsons *et al*.[24] argue that parents/caregivers are often the principal decision makers with respect to a child's health and their perceptions can have a major influence on treatment choice. This is because most health care providers often provide for parents' needs rather than those of children. A parent/caregiver may also be considered as a suitable proxy for young children with cognitive impairment and in those who are too ill to complete the instrument. Furthermore, evidence also shows that dental disease in children results in lost workdays for caregivers as well as time and money spent in accessing dental care.[25] Thus, as part of assessing OHRQOL in children it is important to measure the impact of dental disease on their caregivers and families. Considering the Nigerian situation we focused on the parental/caregivers perception mainly because the reliability and validity of responses from the children were uncertain particularly because the study population included a large number of young children.

Conclusion

Most of the caregivers surveyed consider oral health as affecting the quality of life but did not believe that oral health has an impact on the child's overall well-being. They did not consider emotional well-being as an important component of quality of life. There is a need to design health programs to improve the knowledge of caregivers on the importance of oral health in HIV-positive children as part of the strategy to improve their overall quality of life. Dentists should also be included in the interdisciplinary team that manages HIV-positive pediatric patients for better health outcomes.

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