

Quality of life and oral health experience in HIV-infected and non-infected children

Qualidade de vida e experiência em saúde bucal de crianças com e sem infecção pelo HIV

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ABSTRACT

Objective

Identify and compare quality of life indicators with oral health experience of HIV-infected and non-infected children.

Methods

The study was of the descriptive, exploratory and quantitative type, which was used the modified Autoquestionnaire Qualité de Vie Infant Imagé, consisting of 26 questions with four possible answers and total scores ranging from 0 to 78. The cut-off score was 48, with same or higher scores indicative of satisfaction with quality of life indicators and lower, prejudiced quality of life indicators. To evaluate oral health experience, six questions were added, which used the same score scale as Autoquestionnaire Qualité de Vie Infant Imagé, but that were considered separately. Eighty children from 6 to 13 years old participated in the research. They were divided in two groups: 20 HIV+ (Group 1) and 60 HIV- (Group 2).

Results

The mean scores were 50.45 and 50.8 for Groups 1 and 2, respectively. In relation to the oral health experience, the mean score was 7.0 for Group 1 and 8.6 for Group 2, showing significant differences ($p = 0.0018$). When the subdivision by age (children from 6 to 10 years and from 11 to 13) was considered, significant differences were also observed only for the oral health experience ($p = 0.0165$).

Conclusion

The children interviewed had satisfactory quality of life indicators indicators, while the oral health of HIV-infected children was considered impaired when compared with that of non-infected children.

Indexing terms: Acquired immunodeficiency syndrome. Oral health. Quality of life.

RESUMO

Objetivo

Identificar e comparar os indicadores de qualidade de vida com a experiência em saúde bucal de crianças infectadas ou não pelo HIV.

Métodos

O estudo foi do tipo descritivo, exploratório e com abordagem quantitativa, no qual foi utilizado o Autoquestionnaire Qualité de Vie Infant Imagé modificado, composto por 26 questões com quatro possibilidades de resposta e pontuação total variando de 0 a 78 escores. A nota de corte foi de 48, sendo os escores iguais ou superiores à mesma indicativos de qualidade de vida satisfatória e os inferiores, de prejudicada. Para avaliar a experiência em saúde bucal, foram adicionadas seis questões que utilizavam a mesma escala de pontuação do Autoquestionnaire Qualité de Vie Infant Imagé, mas que foram consideradas separadamente. Participaram da pesquisa 80 crianças dos 6 aos 13 anos que foram divididas em dois grupos: 20 HIV+ (grupo 1) e 60 HIV- (grupo 2).

Resultados

A média geral dos escores foi de 50,45 e de 50,8 para os grupos 1 e 2, respectivamente. Em relação à experiência em saúde bucal, a média dos escores foi de 7,0 para o grupo 1 e de 8,6 para o grupo 2, verificando-se diferenças estatisticamente significantes ($p=0,0018$). Ao se considerar as crianças de acordo com a subdivisão por idades (6 a 10 anos e 11 a 13) também foram observadas diferenças significativas apenas quanto à experiência em saúde bucal ($p=0,0165$).

Conclusão

As crianças entrevistadas apresentaram padrões de qualidade de vida satisfatórios, enquanto que em relação à saúde bucal, as com HIV foram consideradas prejudicadas quando comparadas com as não infectadas.

Termos de indexação: Síndrome da imunodeficiência adquirida. Saúde bucal. Qualidade de vida.

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INTRODUCTION

Since ancient times, quality of life and the pursuit of its improvement have been incessantly sought by human beings, because one of the fundamental characteristics of our species is the eternal desire to live well and constantly envisage new conditions that may our day to day lives more pleasant¹.

The term quality of life covers many meanings and this diversity is partly owing to the influence of at least three characteristics. The first is the historic moment, that is to say, a society also has distinct quality of life patterns in different periods, depending on its economic, social and technological development. The second is cultural, since people construct and organize their needs and values according to their beliefs, customs and traditions. The third refers to social classes, as the concepts of wellbeing are related to status and social stratification².

In the field of health, quality of life assessment has increasingly been used, particularly after confirmation of the legitimacy and reproducibility of its properties of measurement, so that it has been incorporated into the traditional analysis of clinical, laboratory and radiographic parameters, and has become a tool of fundamental importance³. In this panorama, evaluations are considered an essential determinant, considering that it is related to the social, economic, political, and cultural aspects of a society. Therefore, the problem of disease cannot be explained exclusively by the biological factors that characterize them⁴.

In addition to its broader sense, the relationship existent between oral health and quality of life has deserved special attention from Dental professionals, particularly due to the importance of toothache and the physical and psychosocial impacts it causes on the lives of individuals⁵. In this perspective, when it refers to dental treatment, fear becomes cyclic because irregular care of dental pathology by preventive services obliges the use of curative or more invasive and painful practices⁶.

Regarding the group of children and adolescents, their biopsychosocial particularities with reference to the process of growth, personal development (emotional and intellectual maturity) and social inclusion, characterize them as being highly vulnerable to social aggravations and environmental demands, covering different requirement, such as: family, social group and the attention systems (pedagogical, health, social assistance, work, leisure, sports, others)⁷.

In the case of chronically ill children, quality of life assessment allows significant determination of the impact of health care when there is no possibility of cure⁸. Among the chronic illness of great importance to children, HIV infection may be pointed out, considering that with the advent of antiretroviral medications the survival of patients has increased, consequently improving their quality of life⁹. However, new and growing challenges have affected the multiprofessional team that cares for this clientele, due to the doubts, difficulties and worries that arise about adhesion to treatment¹⁰.

Moreover, at present, due to the proportions that the Acquired Immunodeficiency Syndrome (AIDS) has reached, it is considered not only a disease, but the representation of a social phenomenon brought up for discussion values related to sexuality, gender relationships, morals, human rights and life¹¹.

In view of this problem, information about the degree of acceptability of the disease and its influence on psychosocial aspects, family organization, physical performance, elaboration of strategies of confrontation and stressors that may have significant effect on those affected by this illness have been considered extremely relevant. Therefore, the aim of the present research was to identify and compare the general quality of life indicators with experience in oral health of both HIV infected children and non infected children, which may affect their life and wellbeing.

METHODS

The study was of the descriptive, exploratory type, with a quantitative approach, with data being collected in the period between September, 2009 and March, 2010. A total of 80 children of both sexes, in the age-range from 6 to 13 years old participated, and were divided into two groups: Group 1 was made up of 20 children who were diagnosed with HIV infection, and were being cared for at the Hospital Complex for Infectious-Contagious Diseases "Complexo Hospitalar de Doenças Infecto-contagiosas Dr. Clementino Fraga". Group 2 was formed of 60 children not infected by the virus, who were undergoing treatment in the Family Health Program of the suburb Miramar, both in the municipality of João Pessoa, Paraíba. A convenience sample was obtained according to demand of the patients at the establishments and time interval researched. Children with neurological compromise, or who refused to participate, were excluded from the study.

The research instrument used was the "Autoquestionnaire Qualité de Vie Enfant Imagé" (AUQUEI) developed by Manificat & Dazord¹² modified by the suppression of subjective questions, and was applied in the form of an interview, to make it easier to understand. Of the 26 questions of which the questionnaire was composed, 18 were grouped in the function, family, leisure and autonomy domains. The remaining 8 questions were considered separately, as the represented domains separated from the others.

For each question there were four possible answers (very unhappy, unhappy, happy and very happy) with representative images and scores ranging from 0 to 3, respectively. The sum of the scores of all the questions of AUQUEI could range from 0 to 78. After obtaining the total scores, the cut-off score used was 48, with the quality of life considered prejudiced in cases in which the score was lower than this value, and satisfactory for participants with scores equal to or higher than 48.

Experience in oral health was assessed by means of 6 questions drawn up by the authors themselves, with the purpose of obtaining a fast approach that was easy for the participants to understand. The questions referred to the child's relationship with the dentist, its experience when faced with painful stimulus, its perception of caries and the health of oral tissues, and oral hygiene habits. The response options for each question were the same as those proposed in AUQUEI and the identical score scale was also used. Thus, the total score for experience in oral health could range from 0 to 18, and these values were considered separately from those of the other quality of life domains.

Data collection was performed in two different environments. For Group 1, the children were approached after the medical consultation with the pediatric infectologist, and for Group 2, after dental treatment. The interviews were held in the consulting rooms by a single interviewer, with the consent of the child's guardian, however, without his/her presence, so that he/she would not have any influence on the participant. The children were then instructed to indicate the illustration that represented the feeling of their choice for each proposal.

In addition, the children were evaluated according to age and presence or absence of HIV infection, and were divided into subgroups from 6 to 10 years and from 11 to 13 years of age. The data obtained were organized with the aid of the software SPSS (Statistical Package for Social Sciences), version 17.0, and analyzed by means of the Mann-Whitney and Kruskal-Wallis tests with significance of 5%.

The ethical aspects of Resolution 196/96 were observed, and this research was registered in the National Information System under Ethics in Research Involving

Human Beings and unanimously approved by the Research Ethics Committee of the Health Science Center of the Federal University of Paraíba, Protocol No. 0135.

RESULTS

Of the 80 children interviewed in the study, 20 were infected with HIV and formed Group 1, with 9 being boys (45%) and 11 girls (55%). The other 60 children were not infected with HIV and formed Group 2, with 21 being boys (35%) and 39 girls (65%). The mean age of participants in Groups 1 and 2 was 8.7 (with standard deviation of $\pm 2,0$) and $8.4 \pm 2,1$; respectively.

Regarding the AUQUEI scores, the general mean was 50.45 for the children in Group 1 and 50.8 for those in Group 2. Taking into consideration the cut-off score of 48, 65% of the children in Group 1 and 63.33% in Group 2 obtained scores equal to or higher than 48; that is to say, indicative of satisfactory quality of life (Table 1). The percentage distribution of responses to each of the questions may be seen in Tables 2 and 3.

With respect to the experience in oral health, the mean of scores was 7.0 for Group 1 and 8.6 for Group 2. History of the presence of alterations in soft tissues, such as "lumps" and "sores" was reported by 8 (40%) children in Group 1 and 10 (16.67%) in Group 2, while history of toothache was described by 16 (80%) and 27 (45%) of the participants in Groups 1 and 2 respectively. The percentage distribution of responses to each of the questions may be seen in Tables 4 and 3.

When the two groups were statistically compared with regard to quality of life, the Mann-Whitney test indicated that there were no significant differences between HIV+ and HIV- children ($p=0.8585$). When experience in oral health was considered, the same test showed statistical differences between the groups ($p=0.0018$), the assessment of HIV- children being considered better when compared with that of HIV+ children.

In order to compare the groups with and without HIV, also taking age into consideration (children from 6 to 10 years old and from 11 to 13 years old), the Kruskal-Wallis test was used, by means of which statistically significant differences between the two groups were demonstrated ($p=0.6031$). Whereas, when considering experience in oral health and the age sub-groups, the same test indicated significant difference ($p=0.0165$), with the children without HIV obtaining higher scores.

Lastly the presence or absence of HIV infection was compared with each domain of AUQUEI. The Mann-Whitney test indicated no significant difference between the groups ($p>0.05$).

Table 1. Distribution of the quality life assessment according to its classification into satisfactory and prejudiced (consider the percentage by the total number of participants in each group).

Quality Of Life	Group 1						Group 2					
	6-10		11-13		Total		6-10		11-13		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Satisfactory	11	55	2	10	13	65	32	53.3	6	10	38	63.3
Prejudiced	5	25	2	10	7	35	16	26.7	6	10	22	36.7
Total	16	80	4	20	20	100	48	80	12	20	60	100

Table 2. Percentage of responses of children in Group 01 for each of the questions of the Autoquestionnaire Qualité de Vie Enfant Imagé.

Dimension of the quality of life	Very unhappy		Unhappy		Happy		Very happy	
	F (%)		F (%)		F (%)		F (%)	
	6-10	11-13	6-10	11-13	6-10	11-13	6-10	11-13
Function								
At table with the famil	-	-	6.3	-	56.3	50.0	37.5	50.0
When I lie down	-	-	12.5	25.0	62.5	50.0	25.0	25.0
When going to sleep	25.0	-	18.8	50.0	31.3	25.0	43.8	25.0
In the classroom	-	-	6.3	25.0	62.5	50.0	31.3	25.0
Visit to the doctor	-	-	18.8	25.0	37.5	50.0	43.8	25.0
Mean per age group	5.00	0.00	12.50	25.00	50.00	45.00	36.25	30.00
Family								
Play with siblings	12.5	-	6.3	25.0	37.5	25.0	43.8	50.0
Think about my father	18.8	75.0	31.3	25.0	18.8	-	31.3	-
Think about my mother	-	8.3	12.5	25.0	37.5	50.0	50.0	-
Father or mother talk about you	6.3	-	25.0	50.0	37.5	25.0	31.3	25.0
Show something you how to do	6.3	-	12.5	-	37.5	50.0	43.8	50.0
Mean per age group	8.75	16.67	17.50	25.00	33.75	30.00	40.00	25.00
Leisure								
Birthday	-	-	-	-	37.5	25.0	62.5	75.0
During vacations	6.3	-	12.5	-	25.0	25.0	56.3	75.0
Be with grandparents	-	-	6.3	8.3	56.3	50.0	37.5	25.0
Mean per age group	2.08	-	6.25	2.78	39.58	33.33	52.08	58.33
Autonomy								
Play alone	6.3	-	56.3	50.0	25.0	25.0	12.5	25.0
Sleep away from home	25.0	8.3	37.5	-	6.3	50.0	31.3	25.0
Friends talk about you	12.5	8.3	43.8	75.0	31.3	-	12.5	-
Far away from the family	56.3	8.3	31.3	75.0	-	-	12.5	-
Receive school repor	-	-	6.3	25.0	56.3	50.0	37.5	25.0
Mean per age group	20.00	5.00	35.00	45.00	23.75	25.00	21.25	15.00
Individual Questions								
See a photograph of yourself	6	-	6.3	50.0	56.3	50.0	31.3	-
Recreation break at school	-	-	25.0	25.0	18.8	50.0	56.3	25.0
Practice a sport	12.5	-	18.8	25.0	31.3	25.0	37.5	50.0
Do homework	6.3	-	12.5	25.0	75.0	50.0	6.3	25.0
Be hospitalized	43.8	50.0	43.8	25.0	-	25.0	13	-
Take medicines	31.3	-	31.3	25.0	31.3	25.0	6.3	50.0
Think about when I grow up	-	-	6.3	-	43.8	8.3	50.0	75.0
Watch television	-	-	12.5	-	37.5	25.0	50.0	75.0

Table 3. Percentage of responses of children in Group 1 for each of the questions of the Autoquestionnaire Qualité de Vie Enfant Imagé.

Dimension of the quality of life	Very unhappy		Unhappy		Happy		Very happy	
	F (%)		F (%)		F (%)		F (%)	
	6-10	11-13	6-10	11-13	6-10	11-13	6-10	11-13
Function								
At table with the family	-	-	2.1	8.3	72.9	75.0	25.0	16.7
When I lie down	-	-	18.8	25.0	52.1	58.3	27.1	16.7
When going to sleep	-	-	8.3	8.3	62.5	58.3	29.2	33.3
In the classroom	-	8.3	6.3	16.7	70.8	41.7	22.9	33.3
Visit to the doctor	6.3	8.3	16.7	50.0	66.7	25.0	10.4	16.7
Mean per age group	1.25	3.33	10.42	21.67	65.00	51.67	22.92	23.33
Family								
Play with siblings	-	8.3	10.4	16.7	64.6	33.3	25.0	41.7
Think about my father	10.4	16.7	8.3	16.7	58.3	50.0	22.9	16.7
Think about my mother	4.2	16.7	6.3	-	50.0	58.3	39.6	25.0
Father or mother talk about you	4.2	16.7	25.0	8.3	52.1	58.3	18.8	16.7
Show something you how to do	2.1	8.3	4.2	33.3	81.3	50.0	12.5	8.3
Mean per age group	4.17	13.33	10.83	15.00	61.25	50.00	23.75	21.67
Leisure								
Birthday	-	8.3	-	8.3	50.0	50.0	50.0	33.3
During vacations	-	-	6.3	-	43.8	25.0	50.0	75.0
Be with grandparents	4.2	-	-	-	68.8	75.0	27.1	25.0
Mean per age group	1.39	-	2.08	2.78	54.17	50.00	42.36	44.44
Autonomy								
Play alone	12.5	8.3	50.0	50.0	31.3	33.3	6.3	8.3
Sleep away from home	8.3	-	41.7	41.7	39.6	50.0	10.4	8.3
Friends talk about you	4.2	8.3	31.3	33.3	56.3	58.3	8.3	-
Far away from the family	20.8	8.3	60.4	75.0	12.5	8.3	6.3	8.3
Receive school report	-	-	8.3	16.7	62.5	58.3	31.3	16.7
Mean per age group	9.17	5.00	38.33	43.33	40.42	41.67	12.50	8.33
Individual Questions								
See a photograph of yourself	-	-	12.5	16.7	64.6	66.7	22.9	16.7
Recreation break at school	-	-	12.5	-	54.2	50.0	33.3	50.0
Practice a sport	6.3	-	14.6	8.3	47.9	50.0	31.3	41.7
Do homework	4.2	8.3	6.3	16.7	72.9	58.3	16.7	16.7
Be hospitalized	10.4	33.3	56.3	66.7	33.3	-	-	-
Take medicines	4.2	8.3	35.4	75.0	47.9	16.7	12.5	-
Think about when I grow up	2.1	-	2.1	-	68.8	66.7	27.1	33.3
Watch television	-	-	4.2	8.3	66.7	66.7	29.2	25.0

Table 4. Percentage distribution of responses to questions about experience in oral health.

Dimension of experience in oral health	Very unhappy		Unhappy		Happy		Very happy	
	G 1		G 2		G 1		G 2	
	G 1	G 2	G 1	G 2	G 1	G 2	G 1	G 2
When I go to the dentist	20.0	6.7	30.0	10.0	30.0	60.0	20.0	23.3
Perceive that I have caries	20.0	25.0	75.0	65.0	5.0	10.0	-	-
Dentist says I have to have treatment for caries	15.0	3.3	55.0	20.0	25.0	61.7	5.0	15.0
When I have sores in the mouth*	25.0	10.0	75.0	90.0	-	-	-	-
When I have toothache	50.0	44.4	50.0	51.9	-	3.7	-	-
Brush teeth	-	-	5.0	1.7	65.0	70.0	30.0	28.3
Mean per age group	21.7	14.2	48.3	39.7	20.8	34.7	9.8	11.4

Note: G 1: group 1; G 2: group 2. * consider n=8 for Group 1 and n=10 for Group 2. ** consider n= 16 for Group 1 and n=27 for Group 2.

DISCUSSION

Defining quality of life also corresponds to classifying health as good, bad or reasonable, because it arises from the conditions of social class, relationships at work, diet, housing, basic sanitation, healthy environment, access to education, transport, leisure, health services and everything that refers to life⁴. However, measuring it is a very pretentious conquest, because life, a condition indispensable to all beings, demands minimal criteria of quality in order to make it feasible¹³.

After analysis of the data, it was observed that the mean scores for both HIV+ and HIV- children, in spite of being lower, were very close to those found in a study conducted by Assumpção Jr et al.¹⁴ who also used the Autoquestionnaire Qualité de Vie Enfant Imagé questionnaire as research instrument and obtained a mean score of 52.1.

Corroborating the results obtained in the above-mentioned research, it was observed that with small variations, the children in both groups presented greater satisfaction in the questions with reference to the birthday, at table with the family, when thinking about when they were grown up, being with grandparents and watching television. In an analogous manner, the situation of when the child was far away from the family, being hospitalized, playing alone, attained the lowest scores.

Within the family domain, the emotion that the child felt when it thought about its father had a differentiated result for the children infected with HIV when compared with that of the non infected participants and other authors. However, as observed while the interviews were held, it is suggested that this fact occurs due to the absence in almost all cases of the parents during the

child's day to day life, by reason of various factors, such his death, abandonment, or by nominating another relative or tutor to assume to role of provider of the child's needs, also justifying the higher score for questions involving the relationship with the grandmother and mother, as many children considered other relatives as the maternal figure.

With respect to future expectations when they were grown up, the large majority of children in both groups presented positive perspectives. These data confirm those related by Seidl et al.¹⁵, in their research with caregivers of children/adolescents infected with HIV, among whom the majority had hopes that their children would grow up and develop, enjoying quality of life. Moreover, during data collection, it was also observed that the large majority of children interviewed did not know about their seropositive diagnosis, or were not in a condition to understand the dimension of the social representation and severity that accompanied this disease.

With regard to the differences found in the results of experience with oral health, it may be suggested that the lower scores with reference to the infected participants resulted from the stressful circumstances, such as difficulties in obtaining care, disrespect for the child, denial of treatment, or the dentist's negative reaction, as has been related in a study conducted with caregivers of seropositive children/adolescents¹⁶.

Moreover, the non infected children benefited from frequent dental care, and could thus considerably reduce toothache, since more preventive interventions could be performed to prevent the establishment of pathological processes⁵. According to this concept, it also justifies the fact that there were statistically significant differences between the two groups about how they feel when visiting the dentist.

The oral manifestations associated with HIV infection have been well described in the literature (fungal and viral infections, salivary gland alterations, caries lesions, gingivitis and periodontal disease). Nevertheless, in spite of treatment with antiretroviral medications having considerably reduced the frequency and severity of these alterations, the use of these drugs may be related to the increased prevalence of oral lesions associated with infection by the human Papillomavirus, also capable of potentially increasing the risk of future development of oral epidermoid carcinoma¹⁷.

In a study conducted by Massarente et al.¹⁸, it was shown that children with more severe manifestations of AIDS, also complained of more severe oral symptoms, functional, emotional and social wellbeing limitations related to their oral health.

When they perceived that they had carious lesions in their teeth, and when they were informed by the dentist that they had manifestations such as "sores" in the mouth, the children in the groups reacted in a similar manner, demonstrating feelings of unhappiness. However, when they were informed that they needed to treat caries lesions, the majority of children in Group 2 reported a feeling of happiness. In turn, the children in Group 1 felt unhappy in this situation, confirming the previously mentioned view about the experience with dental treatment.

The perception of toothache was shown to be very present among the research participants, so that the majority of the HIV+ and HIV- children replied that they were very unhappy or unhappy when they had toothache, demonstrating that it was a happening that left its mark on them. These data are also important to show that the prevalence of participants who related this feeling was almost the same between the two groups, in spite of the non infected children's greater frequency of visits to the dentist. For some of these children, this corresponded to a happy situation, giving one to understand that they may not have understood the question.

With reference to the toothbrushing habit, the large majority of children affirmed that they felt happy or very happy when they brushed their teeth. These data show that the strategies of oral health motivation and promotion may be effective when well performed, and should therefore be exploited in preventive programs implemented by federal, municipal, and state agencies, and in the communities. Furthermore, toothbrushing twice or more times a day, as well as having one's own mother as caregiver of oral health-related quality of life, reinforces the importance of the care these children need at home¹⁸.

In this study it was observed that the scale used was easy to apply and the interviewed children found it easy to understand, revealing that they are capable of relating their own perceptions and personal experiences about how to live with quality, in spite of being included in a universe of enchantment and ingenuity.

CONCLUSION

The children interviewed presented quality of life indicators considered satisfactory, while in relation to experience in oral health, the scores of HIV+ children were

lower when compared with those of the HIV- children. In this perspective, the importance of the dentist is pointed out as a motivating agent who is qualified and conscious of his/her ethical and legal responsibility in providing health care to patients infected with HIV. Therefore, the need is emphasized for the inclusion of public policies of dental assistance directed towards caring for these patients.

Collaborators

BRM SANTOS was responsible for data collection review of the literature, and writing the article. CAJ ALVES and MB MEDEIROS contributed to data collection and writing the article. HC GALVÃO participated in the bibliographic survey and in writing the article. MRD ROSA guided the research, did the final revision and participated in writing the article.

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