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Original Article

Quality of Life of Paediatric Oncology Patients

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Abstract

Objective: To evaluate the indicators of quality of life (OoL) of children and adolescents with cancer and to evaluate the QoL of participants regarding oral health. Material and Methods: The modified Autoquestionnaire Qualité de Vie Enfant Imagé (AUQEI), with scores ranging from 0 to 78 and a cut-off value of 48, was the instrument used in this study. Questions were added regarding oral health, with scores ranging from 0 to 18. The study consisted of two groups: group 1 (case) consisted of 24 children and adolescents with cancer, and group 2 (control) consisted of 30 healthy children and adolescents aged 6 to 15 years old. A chi-square test was performed using the SPSS program, version 18.0, to determine whether health conditions were related to QoL. **Results:** We observed that 69.25% of participants had scores representing a satisfactory QoL, with a mean score of 54.3 (51.7 for the group of children and adolescents with cancer and 56.5 for the healthy group). The results of the present study showed a value of p=0.016, suggesting that the disease condition is related to lower OoL scores. The Mann-Whitney test showed that the healthy group showed significantly better indicators in the oral health domain. Conclusion: The children and adolescents under study showed satisfactory overall QoL standards; however, when comparing the cancer group to the healthy group, we observed that cancer is associated with lower OoL indicators.

Keywords: Quality of Life; Children; Adolescent; Neoplasms; Oral Health.

Introduction

The assessment of quality of life (QoL), particularly in children with cancer, is used to understand the impact of certain conditions inherent to the diagnosis and treatment of cancer on physical, social, and environmental aspects, to understand the factors that alter well-being and to contribute to the development of policies to optimise the distribution of resources for child development in a healthier manner [1].

Cancer is the second leading cause of mortality in Brazil, and it is responsible for 13% of all deaths worldwide [2]. The most common cancers in children are acute leukaemias, lymphomas, brain tumours, soft tissue tumours (sarcomas), and renal tumours [3,4]. It is known that with an early diagnosis, approximately 70% of childhood cancers are curable. However, the underlying disease and treatment of this specific group of patients produce a series of problems and negative impacts on physical and psychosocial aspects that need to be constantly assessed as part of health surveillance [5-8].

Systemic antineoplastic treatments destroy both tumour cells and tissue cells with high mitotic and cell renewal rates. Therefore, the oral epithelium is highly susceptible and very likely to be affected by chemotherapy drugs. Different complications vary depending on the type of treatment used, and the main complications include mucositis, parotiditis, alterations in taste, xerostomia, pain, opportunistic infections, and spontaneous bleeding in the lips and gingiva [3,9].

The study of QoL with regard to oral health in paediatric oncology patients is necessary because the alterations observed due to antineoplastic therapy condition the eating routine and the interaction of patients as well as impact the treatment, which sometimes has to be stopped to treat opportunistic infections, which compromises the medical therapy and results in a longer period of hospitalisation [10]. Advances in medicine have increased the survival rate but have not necessarily promoted a better QoL for these patients [11].

Thus, the present study aimed to assess the QoL indicators of children and adolescents with cancer, correlating them with the effects that the disease and the treatment produce on oral health.

Material and Methods

Ethical Aspects

The present study was approved by the Human Subjects Research Ethics Committee of the João Pessoa University Centre.

Sample Selection

The sample consisted of two groups: group 1 (G1-test group), which included children and adolescents with cancer of both genders, aged 6 to 15 years old, treated at the Centre for Support of Children with Cancer of the State of Paraiba (Núcleo de Apoio à Criança com Câncer do Estado da Paraíba - NACC-PB); and group 2 (G2-control group), which included children and adolescents in good general health without any previous history of cancer, in the same age group, treated at the

School of Dentistry of the Paraíba Federal University (Universidade Federal da Paraíba - UFPB). Both institutions are located in the city of João Pessoa, state of Paraíba, Brazil. Patients whose general health precluded them from responding to the questionnaires, patients using oxygen masks or with oral mucositis that could compromise talking, and terminally ill patients were excluded from the G1 group. Children with neurologic impairment were excluded from both groups. The pairing of the two groups (test and control) was performed by gender and age group (6-10 years old and 11-15 years old).

Data Collection

The modified Autoquestionnaire Qualité de Vie Enfant Imagé (AUQEI), with suppression of the participant's name and addition of questions related to oral health, was the tool used for data collection. The questionnaire was applied as an interview to facilitate understanding of the children. The AUQEI is a questionnaire that was developed in 1997¹², translated, and validated to Portuguese [13] and comprises structured questions in scale form with four possible answers: very happy (3), happy (2), unhappy (1), and very unhappy (0). The sum of the scores of all answers (ranging from 0 to 78) represents the individual's total QoL related to a specific aspect. After obtaining the total scores, a cut-off of 48 was applied. The QoL of children was considered to be compromised for those with values lower than the cut-off and satisfactory for those with values greater than or equal to the cut-off.

The answers were indicated through representative images that reflect the individual's feelings when faced with conflicts that they experience routinely such as in relationships with family, friends, health care professionals, and other individuals; behaviour in the school and hospital environments, at meals, at play, and during entertainment; knowledge and perception of self-image; performance at school and in the practice of sports; and their future outlook.

Of the 26 questions that compose the original questionnaire, 18 can be grouped in four domains as follows: five questions related to school activities, meals, sleep habits, and physician visits compose the *function* domain; another set of five questions related to the child's opinion regarding parental figures and of themselves compose the *family* domain; three questions that address school breaks, birthdays, and relationships with grandparents are part of the *leisure* domain; and five questions related to independency, relationships with friends, and school assessment constitute the *autonomy* domain. The questions were considered independently because they represent domains that are separate from each other.

As recommended [13], the children were asked, prior to the interviews, to report their own experience for each representative drawing to verify that they were able to correctly identify the corresponding emotional states.

Seven questions elaborated by the authors were added to the original AUQEI within the "oral health" domain that were related to the child's relationship with the dentist and to their self-perception regarding the health of their oral tissues and oral hygiene habits.

After adding the individual scores for each answer on the AUQEI scale, the scores on the QoL assessment in relation to oral health ranged from 0 to 21. Nevertheless, scoring in this domain was considered independently from other domains to avoid interference with the assessment established by the original instrument.

Data collection commenced after signing of the informed consent form by the child's legal representative, according to Resolution number 196/96 of the National Health Council.

G1 participants were recruited at NACC-PB, and G2 participants were recruited at the front desk of the School of Dentistry clinics of the UFPB. In the first case, the interviews were performed in the play area of the institution, while the legal representatives were occupied with other activities at that location. In the second case, permission was requested to interview the child or the adolescent in private so that the participants would not be influenced by the presence of their legal representatives. In the interviews, we recorded the child's age and gender and read the questions for the child to point to the illustration that best represented the feeling of their choice for the proposed statement. After completion, the forms were collected and placed into envelopes without any additional information that could identify the participants.

Statistical Analysis

For the statistical analysis, we employed the Shapiro-Wilk normality test, which indicated that the participants' ages did not follow a normal distribution (p<0.05). Therefore, a non-parametric test (Mann-Whitney) was used to assess the differences between the groups for individual questions. This test was used to assess the significance of the differences between the two groups regarding QoL and oral health QoL. The Chi-square test (χ^2) was used to assess the adequacy of fit between the observed and expected frequencies. For both tests, the significance level was set at 5%. The data were recorded and analysed with the Statistical Package for the Social Sciences (SPSS) software, version 18.0.

Results

G1 comprised 24 children and adolescents with cancer, with 14 (58%) males and 10 (42%) females. G2 included 30 healthy children and adolescents with no prior history of cancer, with 17 (56%) females and 13 (44%) males. The mean ages in G1 and G2 were 9.3 and 9.5 years, respectively. The AUQUEI scores among the children with cancer (G1) ranged from 38 to 67, with a mean of 54.3 and a median of 52. These values were lower than those observed in the healthy group (G2), which ranged from 49 to 69, with a mean of 56.5 and a median of 56.

Regarding QoL related to oral health, G1 exhibited a higher frequency of answers with scores between 7 and 10, with a median of 8. In G2, the scores mainly ranged between 8 and 10, with a median of 9.

In the *oral health* domain, 52% of the children and adolescents with cancer felt happy or very happy when visiting the dentist. In the healthy group, 70% of the participants felt happy in this

domain. According to age group, 50% of the G1 patients between 6 and 10 years old felt happy or very happy when visiting the dentist, while among those between 11 and 15 years old, 81.8% shared the same feeling. In G2, the findings were 88.9% for the participants between 6 and 10 years old and 80.9% for those between 11 and 15 years old.

The QoL scores for 69.25% of the participants were greater than or equal to the cut-off value (48 points), indicating satisfactory QoL, while 30.75% of the participants exhibited lower scores, indicating a compromised QoL. The mean uncompromised QoL scores were 63.0 in G1 and 76.5 in G2 (Table 1).

Table 1. Percentage distribution of QoL assessment of the participants according to gender.

	0										0	
	Group 1					Group 2						•
QoL	6-10 years old (%)		11-1 <i>5</i> years old (%)		Mean (%)	6-10 years old (%)		11-15 years old (%)		Mean (%)	Overall mean (%)	p- value
	F	M	F	M		F	M	F	M			
Compromised (%)	40	33	40	40	37.00	-	10	17	67	23.50	30.75	0.016
Uncompromised (%)	60	67	60	60	63.00	100	90	83	33	76.50	69.25	
Total (%)	100	100	100	100	100.00	100	100	100	100	100.00	100.00	

F: female; M: male

The association between compromised QoL and the presence of cancer in G1 was statistically significant (p=0.016). The differences between G1 and G2 were also statistically significant for overall QoL (p=0.004) and for oral health QoL (p=0.024). The results of each item in the questionnaire for each group are provided in Table 2.

Table 2. Percentage of answers to each question in both groups.

QoL dimension	-	nhappy	Unhappy		Нарру		Very happy	
	(%)		(%)		(%)		(%)	
	G1	G2	G1	G_2	G1	G2	G1	G2
Function								
At the table with family	-	-	-	-	68.0	50.0	32.0	50.0
When going to sleep	-	6.7	-	-	84.0	63.3	16.0	30.0
When sleeping	-	3.3	12.0	-	52.0	66.7	36.0	30.0
In the classroom	4.0	3.3	8.0	3.3	56.0	60.0	32.0	33.3
Medical appointment	20.0	3.3	52.0	26.7	28.0	66.7	-	33.3
Mean by age group	4.8	3.32	14.4**	6.0**	57.6	61.3	23.2**	35.2**
Family								
Playing with siblings	-	-	-	-	56.0	30.0	44.0	70.0
Thinking of your father	-	3.3	8.0	3.3	32.0	33.3	60.0	60.0
Thinking of your mother	-	-	8.0	-	8.0	10.0	84.0	90.0
Mom or dad thinks about you	-	-	12.0	16.7	72.0	66.7	16.0	16.7
Show something you can do	=	-	=	-	18.0	46.7	72.0	53.3
Mean by age group		0.66	5.6	4.0	37.2	37.4	55.2	58.0
Leisure			4.0		40.0	15.0	50.0	00.0
Birthday	-	-	4.0	-	40.0	17.0	56.0	83.0
During vacations	-	=	12.0	-	24.0	10.0	64.0	90.0
Being with grandparents	4.0	-	-	-	36.0	43.3	60.0	56.7
Mean by age group	1.33		5.33		33.3	23.43	60.0	76.56

Autonomy								
To play by yourself	36.0	30.0	44.0	60.0	12.0	6.7	4.0	3.3
To sleep away from home	12.0	-	56.0	10.0	24.0	60.0	8.0	30.0
Friends talk about you	4.0	6.7	36.0	33.3	48.0	53.3	12.0	6.7
Far away from family	36.0	13.3	56.0	60.0	8.0	23.3	-	3.3
To receive school grades	-	-	4.0	3.3	60.0	56.7	36.0	40.0
Mean by age group	17.6	10	39.2	33.32	30.04	40.0	12.0	16.6
Oral health								
Go to the dentist	4.0	3.3	44.0	13.3	36.0	70	16.0	-
Perceive you have dental caries	16.0	36.7	72.0	63.3	12.0	-	-	-
Undergoing treatment of dental	24.0	30.0	48.0	36.7	16.0	33.3	12.0	-
caries	56.0	36.7	44.0	60.0	-	3.3	-	-
Dentist finds cold sores in your	68.0	63.3	32.0	30.0	_	6.7	_	_
mouth	-	3.3	12.0	-	68.0	76.7	20.0	20.0
You have a toothache	4.0	-	12.0	_	44.0	30.0	40.0	70.0
Brush your teeth	T.0	_	12.0	_	тт.0	30.0	40.0	70.0
Meals								
Mean by age group	24.57	24.75	37.71	29.04	25.14	31.4	12.57	12.85
Isolated questions	8.0		24.0	3.3	32.0	40.0	36.0	56.7
Look at a photograph	-	- -	8.0	3.3 -	52.0 52.0	20.0	40.0	80.0
School recess			4.0		76.0	30.0	20.0	70.0
Practice a sport	-	- 		-				
Do homework	-	3.3	20.0	3.3	64.0	46.7	16.0	46.7
Stay in the hospital	56.0	33.3	28.0	63.3	16.0	3.3	-	-
Take medicine	20.0	6.7	60.0	53.3	12.0	36.7	8.0	3.3
Think about when you grow up	-	3.3	-	-	36.0	20.0	64.0	76.7
Watch television	-	-	-	-	64.0	60.0	36.0	40.0
Mean by group	12.0**	5.82**	18.0	15.4	44.0	32.08	27.5**	46.75**

^{**} Significantly different values (p<0.001).

Discussion

A comparison between a group of children and adolescents with cancer under antineoplastic treatment and without cancer shows that grievances are common and identifies those that are inherent to patients with the disease and under treatment. The results also demonstrate the effect of these factors on QoL, noting those that can be altered by health professionals to improve the physical, psychological, and social well-being of paediatric oncology patients.

With the employment of a questionnaire suitable for the collection of information from children and adolescents and according to their cognitive function, it is possible to adequately collect well-being and functional status information using strategies and methods that include different answer categories with figures or pictograms [11,14], which is the case with AUQEI used in the present study.

The QoL of the majority of the participants in both groups was satisfactory in terms of their AUQEI scores. However, a larger number of subjects in G2 than in G1 had a satisfactory QoL. This difference was associated with the presence of cancer and corroborates the results of a previous study conducted in Canada [15] that included 206 children and adolescents between 5 and 18 years old with acute lymphocytic leukaemia. In that study, the scores showed a compromised QoL.

When comparing the two groups, the mean scores of children and adolescents with cancer were lower than the scores of healthy subjects, and similar when comparing the QoL scores of

children with cancer with scores found in previous study that applied the AUQEI in children with caries [16].

The dispersion of scores in children with cancer was lower than in the healthy group. Participants in G2 provided more answers in the "happy" and "very happy" categories than in G1. Thus, children and adolescents who are ill feel less happy than those who are healthy.

In the *function* domain, the majority of the G1 participants reported being unhappy or very unhappy at the medical office, while less than half of the participants in G2 provided similar answers. It is presumed that the difference in feelings between the two groups is due to the experiences of medical visits, as patients in the healthy group do not necessarily have negative memories regarding this item; however, in the cancer group, the experiences are more traumatic, likely because patients receive the diagnosis of their disease and undergo frequent admissions for diagnostic tests and treatment in the healthcare environment.

The family domain was the item for which children and adolescents in both groups felt happiest. The most satisfactory answers corresponded to "thinking about your mom" and "show something you know how to do" in G1 and "playing with siblings" and "thinking about your mom" in G2. Although a large percentage of participants in both groups reported being "very happy" when they think about their parents, a large difference was observed when fathers and mothers were compared, perhaps due to mothers being more protective during childhood. In the case of cancer patients, this feeling was even more significant, given that in most cases mothers accompany the patients in all treatment stages, representing a foundation for coping with the disease. This result is reaffirmed in another study [17] that shows that the family is involved in the complex and dynamic care of children and adolescents with cancer.

Regarding the greater sense of happiness in the cancer group when showing "something that you know how to do", it is assumed that patients in this group feel valued by showing that, despite the disease, they did not become incapacitated. However, regarding the question regarding "playing with siblings", patients in G1 do not feel as happy as those in G2. The explanation for this finding may involve the fact that children with chronic diseases do not feel very happy to play with siblings due to the reduced desire for play and the constraints of treatment [18].

In the *leisure* domain, children and adolescents in G2 reported higher percentages of feeling "very happy" on "birthdays" and "during vacation" than participants in G1. It is suggested that the difference between the two groups is due to limitations of the disease and treatment that prevent patients from enjoying these events as they would like [10].

In the *autonomy* domain, more than half of the children with cancer said they were "unhappy" or "very unhappy". The answers expressing low QoL in this domain were mainly related to the items "play by yourself" and "stay far away from family". In G1, most children and adolescents felt "very unhappy" or "unhappy" when playing by themselves. When they thought about staying far away from family, a very small portion of children reported feeling "happy" or "very happy". This was the item with the most negative findings in the validation study of AUQEI in Brazil [13].

Similarly, in the "isolated questions" domain, some questions showed that the influence of cancer seems to be critical, with a higher percentage of responses denoting impaired QoL in G1 than in G2. To mediate these factors and to reduce the interference in QoL, playful activities have been adopted in hospital environments, which have shown positive results, reducing the negative effects of hospitalisation and withdrawal from daily activities, friends, and favourite play activities of each child [19, 20].

The "self-concept" was shown to be compromised, with less than half of G1 stating that they felt "very happy" about the statement "see a picture of yourself", while in G2, the percentage of subjects who gave the same response was more than half. It is possible to infer with this finding that the group with cancer had a greater perception of the physical consequences of the disease and the treatment, especially in the oldest age group, as it is common in older children to have an increased concern with physical appearance [21]. The compromised "self-concept" was also observed in adolescents with cancer in Morocco, showing that of 23 Moroccan teenagers, 20 felt ashamed of losing their hair, and of these, 15 teenagers had depression [6].

Regarding the "stay in the hospital" item, patients in G1 answered "very unhappy" more often than those in G2. The same result was observed for the "take medicine" item. This difference is associated with the fact that cancer patients are subjected to multiple hospitalisations and require routine use of aggressive medications during treatment, causing a greater impact related to these situations [5].

The answers to the items "play at recess" and "practice sports" were favourable to QoL, a result that has also been observed in previous studies [6,13,22]. However, if the answers "happy" and "very happy" are taken into account, we would consider that children and adolescents with cancer have compromised QoL compared to healthy children and adolescents. Moreover, on the "practice sports" item, a small number of children and adolescents with cancer said they feel "very happy", while this amount was more than double for the healthy group. This discrepancy can be attributed to the pain and physical limitations that prevent or hinder this practice in the cancer patient group [20].

For the "isolated questions", it was observed that all children and adolescents of G1 were hopeful about the item "think about when you grow up", giving only "very happy" and "happy" answers, demonstrating that they are optimistic when thinking about the future, despite experiencing all of the disease process [21]. In general, after overcoming the effect of receiving a diagnosis of a lethal disease, the patient tends to believe that it can be a transitory event and starts thinking about healing and making plans for the future [23].

In the *oral health* domain, we found that G2 patients reported happier feelings when going to the dentist than children and adolescents in G1. In G1, half of the children and adolescents in the 6 to 10 year old age group were "happy" or "very happy" when visiting the dentist, while a greater number of those in the 11 to 15 year age group had the same feeling. In G2, the percentages were

high for both age groups but higher in the 6 to 10 year old age group. The results of the present study differ from a study that found older children to be more afraid of dental treatment [24].

When informed by the dentist about having mouth "sores", G1 patients showed greater unhappiness. Mucositis is one of the most common consequences of antineoplastic therapies [5,25-27]. The higher rates of unhappiness due to "cold sores" may be associated with the fact that mucositis causes pain and discomfort and, depending on the severity, prevents patients from eating and exercising proper hygiene habits.

Reinforcing these findings, the reports of children and adolescents with cancer and their caregivers indicate that due to the complications derived from the antineoplastic treatment, it is essential to establish educational, preventive, and curative strategies in oral health before, during, and after treatment. This action can help to seek resolution and/or minimise the discomfort reported by patients and improve the QoL of these children and their families [28].

Regarding the "toothache" item, both groups responded negatively, which shows the extent that this condition interferes with QoL. The vast majority of children and adolescents reported feeling "happy" about the habit of brushing their teeth and at meal time; however, some children and adolescents in G1 reported feeling "unhappy" with these items. We assume that this finding is related to complications of antineoplastic therapy such as mucositis, considering that a recent study found that lesions in the oral mucosa negatively affect QoL [29].

Few studies in the literature associate oral health and QoL of cancer patients. An even greater shortage of studies exists concerning children and adolescents because studies that investigate oral health and childhood cancer are limited to treatment sequelae in the oral cavity and not the impact on QoL. Thus, the present study contributes to a better understanding of the QoL patterns associated with oral health. However, it emphasises the need for new studies that focus on the importance of integrating dental visits into the multidisciplinary care of children and adolescents with cancer.

The present study has limitations. Among the disadvantages of research performed through interviews are the interviewees' lack of understanding of the questions and the lack of motivation in answering the questions, especially for sick children. Nevertheless, the present study reflects the emotional condition and the limitations faced by paediatric cancer patients.

Conclusion

Cancer has a negative influence on the QoL of children and adolescents with the disease. Children and adolescents with cancer had a compromised QoL compared to healthy children and adolescents as demonstrated by the greater percentage of negative responses such as "unhappy" and "very unhappy" in all domains in the cancer group. The cancer group showed lower rates of satisfaction mainly in the *autonomy* domain and in "isolated questions", in which the evolution of morbidity and treatments influences their physical status, such as in the practice of sports and appearance in photographs. Regarding the oral health domain, children and adolescents with cancer

showed compromised QoL compared to healthy children, indicating the effect of sequelae produced by antineoplastic treatment on the oral health of patients.

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