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RESEARCH ARTICLE

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# Perception of Pediatric Oncological Patients and Their Parents/Guardians about a Hospital Oral Health Program: A Qualitative Study

Maria Eduarda Alves Sampaio<sup>1</sup>, Isabella Lima Arrais Ribeiro<sup>2</sup>, Bianca Marques Santiago<sup>2</sup>, Ana Maria Gondim Valença<sup>2\*</sup>

## Abstract

**Background:** The oral healthcare offered to pediatric cancer patients at the hospital level must include educational and preventive strategies based on dialogical and welcoming professional attitudes. Therefore, the current study aimed to evaluate the perception of pediatric cancer patients and their parents/guardians about an educational and preventive oral healthcare program implemented in a reference hospital for cancer treatment. **Methods:** A qualitative follow-up investigation was conducted in which we evaluated the perception of pediatric cancer patients and their parents/guardians regarding an educational and preventive oral health program (OHEPP). The participants were 27 children and adolescents undergoing cancer treatment and their parents/guardians, and the assessment was carried out at 15 and 30 days after beginning the program through semi-structured interviews. The program used audiovisual resources, storytelling and playful instruments for the oral health education of patients and parents/guardians. The interviews were then transcribed and the Discourse of the Collective Speech (DCS) technique was performed for data analysis. **Results:** Patients and parents/guardians reported improvement in oral hygiene habits and conditions. Patients reported greater enthusiasm for oral care and highlighted the recreational aspect of the program. Parents/guardians reported being more clear about oral changes and paying attention to the appearance of comorbidities resulting from anticancer treatment. **Conclusions:** This study suggests that implementation of the oral health program favored communication between health professionals, patients and their parents/guardians, expanding knowledge and generating behavior change in oral healthcare.

**Keywords:** Oral health- pediatric dentistry- oncology service- hospital- dental health education

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## Introduction

The risk of life inherent to cancer and the symptoms associated with its treatment have physical, psychological and social impacts on patients (Jibb et al., 2018). Children and adolescents often perceive antineoplastic therapy as something unpleasant and restrictive, and they suffer from separation from family members and friends given the long and frequent hospitalization periods (França et al., 2018).

Cancer treatment is also capable of generating significant adverse effects in the oral cavity, which may negatively impact the oral health of cancer patients (Sonis and Yuan, 2016). Oral mucositis, gingival bleeding, dry mouth, viral and fungal infections are among the oral complications of treatment and these manifestations are more frequent in children than in adults (Velten et al., 2017). Oral mucositis is identified as the most debilitating complication of cancer treatment (Zhu et al., 2017). It

is characterized by inflammation of the mucosa which lines the oral cavity, with an appearance of erythematous areas which can develop into large ulcers (Peterson et al., 2012). There are situations of intense pain and risk of secondary infection from ulcers, even requiring to reduce or suspend cancer treatment, which can worsen the patient's prognosis, which demonstrates the importance of managing this condition (Sonis and Yuan, 2016). Moreover, there is risk of sepsis related to degree of oral mucosal barrier breakdown (Peterson et al., 2015).

Some studies show that care measures and education in oral health can reduce the severity of oral mucositis in children under antineoplastic treatment (Cheng et al, 2004; Yavuz and Yılmaz, 2015). Therefore, oral care programs are considered viable and effective strategies to prevent oral mucositis in pediatric cancer patients (Qutob et al., 2015).

A relevant aspect to be considered in cancer patients is the change in their lifestyle caused by frequent and

<sup>1</sup>Graduate Program in Dentistry, Federal University of Paraíba, João Pessoa, Brazil. <sup>2</sup>Department of Clinics and Social Dentistry, Federal University of Paraíba, João Pessoa, Brazil. \*For Correspondence: anamvalenca@gmail.com

prolonged hospital stays (França et al., 2018). Changes in daily dynamics can impact self-care, making it difficult to maintain adequate behaviors to maintain oral health during antineoplastic treatment (Cheng, 2009). In this scenario, the importance of the dentist's role in the oncology team is evident, as it is possible to minimize oral complications resulting from antineoplastic therapy through practicing routine oral care and early diagnosis of changes which can negatively impact cancer treatment (Velten et al., 2017; Ribeiro et al., 2021). Regarding this aspect, we instituted a planned mouth care education program to pediatric cancer patients - Oral Health Education and Prevention Program (OHEPP) and it was effective to reduce the incidence of oral mucositis in these patients (Bezerra et al., 2021).

Therefore, this study aimed to evaluate the perception of pediatric cancer patients and their parents/guardians about this educational and preventive oral healthcare program (OHEPP) implemented in a reference hospital for cancer treatment.

## Materials and Methods

This qualitative follow-up investigation was methodologically guided by the Discourse of the Collective Subject (DCS) method and it was conducted from April to October 2018. The Paraíba Federal University Research Ethics Committee approved the study (CAAE: 83179518.4.0000.5188). The Informed Consent Form (ICF) was applied to parents/guardians and the Informed Assent Form (IAF) was applied to patients over twelve years of age. This article follows the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist (Tong et al., 2007).

### Study setting

The Hospital Napoleão Laureano (HNL) is located in João Pessoa, a city located in the northeast region of Brazil. Approximately 392,278 outpatient visits and 5,509 outpatients are performed annually at this location. The hospital has an operating room, clinical and pathological analysis laboratories, radiology, radiotherapy, chemotherapy services, adult and pediatric ICU, outpatient clinic and adult and pediatric wards. The pediatric ward has 21 beds and the pediatric ICU has six beds.

### Study participants

The population consisted of all cancer patients receiving care in the pediatric sector of the hospital

from April to October 2018, their parents/guardians. The research subjects included in the study were patients aged 4 to 19 years undergoing cancer treatment and their parents/guardians, who had to be present during the data collection period. Patients with compromised health status (n=9) or who did not consent to participate in the study (n=6) were excluded.

The research sample consisted of 27 children/adolescents and 27 parents/guardians.

### Study procedures

Individuals were approached and invited to participate in the study soon after hospital admission, or before the next chemotherapy cycle. The next day, they individually received an educational and preventive program in oral healthcare by a member of the research team (MEAS, female) who has extensive experience in caring oncopediatric patients at the hospital where the research was conducted. The participants were made known, prior to the study, that the researcher was a qualified dentist and a postgraduate student of health care.

Patients over 12 years old and their parents/guardians were invited to watch an educational video lasting approximately seven minutes. The video content covered the following themes: cancer treatment modalities; repercussions of chemotherapy and radiotherapy in the oral cavity; main oral problems related to cancer treatment; etiology, prevention and treatment of oral mucositis; guidelines on oral hygiene and the use of fluoride.

Patients over 12 years of age and their guardians also received inserts addressing the following topics: importance of dental monitoring of cancer patients; etiology, prevention and treatment of the main oral problems related to antineoplastic therapy; importance of oral hygiene; caries etiology and measures to prevent this disease; and oral hygiene guidelines. In the case of younger patients, oral health information was transmitted through storytelling and the use of playful instruments. The patients received a diary of oral care practices, in which they (or the person responsible) recorded their oral hygiene procedures performed each week, and a gold star was attached to the diary for each day that toothbrushing and tongue cleaning were performed at least twice. In addition, a card related to the patient's performance was filled with face stickers corresponding to the patient's conduct in that week. Oral hygiene orientation (OHO) was performed directly with each patient. Children and adolescents were asked to demonstrate how they normally

Chart 1. Script of Semi-Structured Interviews Applied to Patients and Guardians in Relation to Their Perception of the OHEPP

Questions	Patients	Parents/Guardians
1	Do you think you have changed anything in your oral health habits after the oral health activities performed at the hospital? What things?	Have you noticed any changes in your child's oral health habits after activities performed at the hospital? What are they?
2	From 1 to 5, how much do you think your oral health habits have changed? (where 1 means that nothing has changed, and 5 that it has changed a lot)	From 1 to 5, how would you rate your child's change in oral health habits? (where 1 means that nothing has changed, and 5 that it has changed a lot)
3	What did you think of the activities?	What is your opinion about the oral health activities performed at the hospital?
4	Do you have any suggestions for performing oral health activities?	Do you have any suggestions for performing oral health activities?

Chart 2. Responses from Pediatric Cancer Patients about the OHEPP

Period	Question	Central Idea (CI)	Patients
			Discourse of the Collective Subject (DCS)
15 days (n=17)	1	Habits changed Improved hygiene	Yes, I'm brushing my teeth more and better. You gave me tips that helped a lot to improve the way I brush and moisturize my lips.
	3	Nice/good Feel better	I like it. It's good to talk to you [...] It improved a lot, after I got into the habits, I started to feel better, like I wasn't before [...] I'm much better, it's a matter of habit, once I get the hang of it, it's good.
	4	No suggestion	No, it's good the way it is...
30 days (n=17)	1	Habits changed Improved hygiene Increase in the brushing frequency	Yes, actually, I didn't even care about teeth hygiene before. After the advice the dentists gave me, it ended up influencing my oral hygiene and improving a lot [...] Before, I only brushed in the morning and didn't brush in the afternoon or at night. Now you are teaching me and I'm brushing more. [...] I pay more attention to the parts of the teeth that are still dirty even after brushing.
	3	They are good Teaching brushing technique OM prevention	They are good, because they teach you to brush your teeth better and prevent mucositis [...] I like it a lot because, in addition to relaxing, you are also taken care of. I thought it was cool, because taking care of health is essential and oral health is very important [...] It's cool because it gives the child motivation to brush their teeth so that mucositis and other diseases do not appear. Even my sister is brushing, even though she is not undergoing treatment, but even so she can get diseases like teeth falling out and other things.
	4	More toys	No, it's great the way it is [...] But if there were more toys it would be better.

brush their teeth and then they were guided on the correct brushing technique through simulation on a model. Afterwards, they were invited to practice the technique on the model, and finally they performed it in front of the mirror.

We opted for the modified Bass brushing technique (Bass, 1954) and the recommended amount of dentifrice followed the American Dental Association criteria for each age group (American Dental Association Council

on Scientific Affairs, 2014). The OHO was reinforced every two weeks, and each week the patients received a diploma with a grade on their oral hygiene performance. Patients also received gold or silver medals according to their behavior in relation to the oral health program. Soft brushes (manual children's brush with soft bristles - Colgate®) and fluoridated toothpaste (1,100 ppm of fluoride, Colgate® Maximum Anticavity Protection plus Neutraçucar®) were provided to the patients in a

Chart 3. Responses from Caregivers about the OHEPP

Period	Question	Central Idea (CI)	Guardians
			Discourse of the Collective Subject (DCS)
15 days (n=27)	13	Improved oral hygiene Improved brushing technique Improvement of oral mucositis More stimulated patient	It improved mouth cleaning and improved the gums [...] he was too lazy to brush his teeth and now he brushes more often and better [...] Before I brushed for brushing, now because they encouraged brushing [...] the "thrush" isn't appearing anymore.
	3	Very important OM prevention Gingivitis prevention Guardians more attentive to oral hygiene care More cooperative patient	I think it's great [...] it's very important to prevent oral mucositis and gingivitis [...] and it helps a lot to pay more attention to the child, to stop more, especially when brushing the tongue, as explained [...] It's very interesting, because it not only helps with care, but the child also has this concern. I talk to her at home, but when someone else is talking, she pays more attention [...] It helps us with daily cleaning, because we often have the difficulty of knowing if it's right or not, we get to know, and can provide more suitable cleaning for them.
	4	Oral healthcare extended to guardians	For me it's fine as it is. Continue! [...] What you do with him is already so fantastic. In a dynamic, funny way, he manages not to be afraid, he can see the dentist as a good thing, because it becomes something pleasurable [...] It would only be better if care were extended to the mothers. We stay with the patient and don't have time to go to the dentist. His oral health may improve and his mother's may worsen.
30 days (n=25)	1	More stimulated patient Awareness of the importance of oral hygiene Gum improvement Lower consumption of sweets Increased frequency of toothbrushing Be careful of tongue brushing	Yes. Before, he didn't let him brush at home and then he changed. He started wanting to brush more [...] He understood the need to brush his teeth. The habit of brushing has changed for the better [...] I noticed his teeth whitening and an improvement in his gums [...] Before he ate a lot of sweets, now he doesn't and when he does, he brushes properly [...] It increased the amount of brushing, care in brushing the tongue, because she didn't have this habit [...] He's asking a lot to brush his mouth.
	3	Very good Doubts clarified Guardians more attentive to brushing Prevention of mucositis and other health problems	It's very good because there's nothing in his mouth after chemotherapy [...] We see that it's very cool, because it helps us a lot, if we have any questions, you can answer them, it makes us more attentive and brushing daily [...] is important. In addition to the care, it also prevents mucositis, preventing a greater problem in the mouth in relation to medications [...] It's important not to be like the other patients I used to see up there.
	4	More toys Do it in the afternoon	It's great as it is [...] because even the games teach brushing [...] but there could be more toys and it could be in the afternoon.

Table 1. Demographic and Clinical Characteristics of Pediatric Cancer Patients

Variable	n	%
Gender		
Male	14	51.9
Female	13	48.1
Skin color		
Brown	18	66.7
White	8	29.6
Black	1	3.7
City of residence		
Other cities in Paraíba	21	77.8
Capital and metropolitan zone	6	22.2
Tumor type		
Hematologic neoplasm	14	51.9
Solid tumor	13	48.1
Treatment		
Chemotherapy	17	63.0
Chemotherapy and Radiotherapy	4	14.8
Chemotherapy and Surgery	4	14.8
Chemotherapy, Radiotherapy and Surgery	2	7.4
Patient status		
Recent diagnosis	20	74.1
In treatment	7	25.9

standardized way during the study.

Data collection took place in two stages with semi-structured interviews being conducted with patients and guardians 15 and 30 days after beginning the program, with the aim of providing knowledge of the changes implemented by it. Interviews were conducted by the same trained research (MEAS) who has a relationship established prior to interviews. However, it was made clear that she was conducting this study as an impartial researcher. The interviewer had experience in qualitative research methods and in working with childhood cancer patients in pediatric units. Interviews were audio-recorded and contained four open questions related to the perception of patients and guardians in relation to the program (Chart 1). Interviews lasted approximately five minutes and patients under 6 years old were exempted from responding. Transcripts were not returned to participants for review and no repeat interviews were conducted.

#### Analyses

The audio recording of interviews was transcribed, and one author (MEAS) coded the data. The speeches of interviewees were identified by the letter P (patient) or letter G (guardian) and the number of realizations of order, such as P1, P2, G1, G2 and beyond. The Discourse of the Collective Subject (DCS) analysis started with a thorough reading of the transcripts to identify recurring ideas, words, or phrases, and belief patterns were identified and each of the core ideas and their corresponding key expressions were extracted. Thus, the key expressions (KE) for each of the groups (patients and parents/guardians) were initially

identified, and then the central ideas (CI) were extracted. Finally, with the sum of key expressions and central ideas, the synthetic discourses representing the collective subject discourse were constructed (Lefevre and Lefevre, 2005).

## Results

### Characteristics of the sample

The study included 27 children and adolescents assisted in the Pediatric Oncology sector of Hospital Napoleão Laureano and 27 parents/guardians. The mean age of patients was 9.41 ( $\pm 4.49$ ) years. Table 1 shows the demographic and clinical characteristics of the children and adolescents who participated in the study.

### Perception of patients and guardians in relation to OHEPP

From analyzing the interviews of patients in the periods of 15 and 30 days, the categories which emerged and the speeches representing these categories can be seen in Chart 2. Patients were asked in the second question during the interviews about how much they thought their oral health habits had changed from implementing the program. The answers could range from one to five, where 1 meant it did not change anything, and 5 meant it changed a lot. It was observed that 47.1% (n=8) of the patients classified the change as 5, both in the 15-day period and for the 30-day period and 35.6% (n=6) of them classified the change as 4, while 41.2% (n=7) gave the change a grade of 4 for the 30-day period.

The patients' reports for the two evaluated periods suggest the positive impact of the OHEPP on oral hygiene habits. Changes in brushing frequency and technique were mentioned, as well as the recreational aspect of the program for children and adolescents. Thus, some main themes emerged following the analysis and Chart 3 illustrates the categories and reports of the guardians for the periods of 15 and 30 days.

Parents/guardians also considered the positive impact of the program, both on the patients' oral hygiene habits and on the improvement in oral mucositis. They mentioned that the patients were more stimulated and cooperative after the playful activities were developed, and they themselves were more informed and attentive to the prevention of oral mucositis and other health problems. When caregivers were asked about the perceived change in the patient's oral health habits (question 2) within 15 days, 59.3% (n=16) of them classified the change as 5, while 60.0% (n=15) gave the change a grade of 5 for the 30-day period. Moreover, 29.6% (n=8) and 32.0% (n=8) caregivers classified the change as 4 for the 15-day and 30-day periods, respectively.

## Discussion

This study reveals that children and adolescents undergoing anticancer treatment need to more carefully look at oral healthcare, seeking individualized care. Strategies based on dialogue and welcoming professional attitudes are essential in oral healthcare from the

perspective of expanding the knowledge of patients and their parents/guardians about possible changes in the oral cavity resulting from cancer therapy. Our study showed that the educational and preventive program implemented favored communication between the oral health team and the research participants, health professionals, patients and their parents/guardians. We emphasize that this approach is still little explored in the field of pediatric oncology.

Regarding the demographic and clinical characteristics of the study participants, it was found that patients with hematologic malignancies and who lived outside the capital/metropolitan area predominated. It is important to highlight that hematological neoplasms can have several consequences for the oral cavity, such as ulcers, petechiae, trismus, oral infections, bleeding and gingival hyperplasia (Francisconi et al., 2016). Leukemic cells have the ability to invade periodontal tissues, causing swelling, bleeding and gingival inflammation, characterizing the picture of leukemic infiltration (Mazaheri et al., 2017). These gingival changes cause fear in patients and their caregivers in relation to oral hygiene, and can be neglected (Cheng, 2009).

Another point to be highlighted is that patients living in locations far from the capitals face challenges for cancer treatment, including financial and transportation barriers. The large distances traveled to treatment centers can make traveling to specialized treatment centers a stressful process for patients and their guardians (Carneiro et al., 2015). The relationship with family and friends can also be affected by the physical distance imposed by cancer treatment, generating a psychological impact on patients and their families (Bakula et al., 2019). These emotional changes can impact self-care, pointing to the importance of instituting a program which encourages oral care during antineoplastic therapy.

Cancer treatment obviously imposes a change in the patients' lifestyle, generating restrictions in several aspects, and interfering with the child's most routine activities such as playing (França et al., 2018). The recreational activities carried out in the hospital environment are described by pediatric cancer patients and their caregivers as something positive, an important incentive and complement to regular care (Ljungman et al., 2016).

The lack of recreational activities at the cancer hospital is not only a frequent complaint from patients, but also from caregivers (Cheng, 2009; Jibb et al., 2018). From this perspective, the playful aspect of the program developed in this study facilitates involving children and adolescents in the proposed activities, giving them the opportunity to play while assimilating the topics covered. Patients mentioned that they felt better when adhering to the proposed oral care, also referring to the importance of the program for preventing oral mucositis and that they were even influencing their family members to adopt more adequate oral hygiene habits. Increased vigilance in relation to oral changes resulting from antineoplastic treatment is essential, and by maintaining oral care it is possible to minimize some oral complications and to provide comfort (Elad et al., 2018; Yavuz and Yilmaz, 2015). Early diagnosis and treatment of these complications can also prevent more severe conditions, with the potential

to negatively affect cancer therapy (Ribeiro et al., 2021).

Oral health interventions and education are able to reduce the severity of oral mucositis in children and adolescents undergoing cancer treatment (Yavuz and Yilmaz, 2015; Ribeiro et al., 2021). These data corroborate the guardians' statements regarding the improvement in hygiene habits and in the patients' oral mucositis condition after implementing the OHEPP. Moreover, we emphasize that this oral health program reduced the risk of developing oral mucositis in pediatric oncological patients (Bezerra et al., 2021).

Pediatric cancer patients and their guardians often show signs of stress and psychological changes after diagnosis (Bakula et al., 2019) and these children and adolescents may demonstrate resistance to oral care (Cheng, 2009). In this logic, an educational and preventive oral health program becomes relevant as it encourages adopting good hygiene habits and oral health surveillance, preventing patients and guardians from neglecting these issues due to difficulties related to cancer treatment.

A qualitative approach study reported that children, despite being aware of the importance of oral care, sometimes neglected oral hygiene due to the discomfort associated with oral mucositis (Cheng, 2009). Parents described the oral hygiene moment as being stressful for their children and for themselves. Guardians also stated that the health team should carry out more activities to distract children from their oral mucositis. In addition, they mentioned the need for more information regarding this disease. Regarding this aspect, previous studies demonstrate that guardians and patients themselves refer to the need for more accurate information about cancer treatment and its adverse effects. The lack of adequate communication between the medical team and the family can be stressful and traumatic (Lyu et al., 2019; Robertson et al., 2019).

Thus, the OHEPP has a relevant informative character, as it clarifies the main oral manifestations related to antineoplastic therapy and the prevention and treatment forms, thus enabling both patients and caregivers to feel more enlightened and secure in relation to the course of treatment. Proving this aspect, the OHEPP was effective in reducing the incidence of oral mucositis in these in pediatric cancer patients (Bezerra et al., 2021).

It is important to emphasize that comparisons of the results of this study with those found in the literature were limited due to the scarcity of studies which assess the perception of patients and guardians about oral health programs implemented in the hospital environment. The few studies which have proposed to investigate the subject only assess the impact of oral health programs in a quantitative way, without considering the speeches of patients and their parents/guardians.

Considering the difficulty in measuring values and opinions quantitatively, this work demonstrates its relevance and uniqueness in analyzing the perspective of children and adolescents with cancer and their parents/guardians on an educational and preventive oral health program, exposing their expectations and propositions in relation to the work developed.

Although our study produced relevant data, it had

some limitations. One limitation is related to the restricted context of data collection and the cultural and geographic specificities of the participants and the study setting. It should also be considered that the young age of some patients and the low level of education of some parents/guardians may have limited their ability to answer certain questions more clearly.

However, the results of this study are relevant and represent an important source of information to guide developing and implementing oral care programs for children and adolescents undergoing cancer treatment, which may reflect in improved quality of life and have a positive impact in cancer therapy, reducing situations related to the increase in hospitalization time and an increase in treatment costs.

It is concluded that the OHEPP helped to improve knowledge and attitudes related to oral health, favored adopting and/or increasing the frequency of oral hygiene habits and provided increased surveillance in relation to the appearance of oral changes resulting from antineoplastic treatment for pediatric cancer patients and their parents/guardians.

## Author Contribution Statement

Conceptualization: M.E.A.S., A.M.G.V., B.M.S., I.L.A.R.; Methodology: M.E.A.S., A.M.G.V., B.M.S., I.L.A.R.; Formal analysis and investigation: M.E.A.S., A.M.G.V., B.M.S., I.L.A.R.; Writing - original draft preparation: M.E.A.S., A.M.G.V., B.M.S., I.L.A.R.; Funding acquisition: M.E.A.S.; Supervision: A.M.G.V., B.M.S.

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### Ethical Statement

The study was approved by the Research Ethics Committee of the Federal University of Paraíba (Protocol number 83179518.4.0000.5188).

### Availability of data

The data that support the findings of this study are available from the corresponding author upon request.

### Conflict of interest

The authors have no conflicts of interest to declare.

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