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Original Article

Access to and Satisfaction with Oral Health Care from the Perspective of Pediatric Cancer Patients and Their Caregivers

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Abstract

Objective: To investigate the access to dental care and the oral health care provided to cancer patients aged zero to 19 years old; to detect possible difficulties hindering the delivery of oral health care; and to identify the main oral complications associated with anticancer treatment. **Material and Methods:** Interviews were conducted with 84 children and adolescents (or their caregivers) who were treated at Napoleão Laureano Hospital, João Pessoa County, Paraíba, Brazil; the interviews were recorded in audio files. The data were analyzed based on systematic reading of the interviews according to the content analysis technique. **Results:** Six categories were established: Access to health care services, which was reported as posing difficulties by only 16.6% of the sample; Access to the hospital, considering that 40.4% of the participants reported traveling to the hospital in cars provided by the city government; Dental care, which was procured at basic health units (BHUs) by 52.3% of the participants; Conceptions on oral health care, in which 64.2% of the participants mentioned cariogenic diets and/or poor oral hygiene; Quality of life perception, whereby 70.2% of the interviewees reported to be satisfied or very satisfied and 63.0% rated their quality of life good or very good; and Health problems derived from treatment, with nausea being the most mentioned (27.2%). **Conclusion:** The patients did not meet difficulties in the procurement of dental care, which was most often sought at BHUs; they were satisfied or very satisfied with their health and rated their quality of life as good or very good.

Keywords: Health promotion; Neoplasms, Child; Adolescent.

Introduction

Diagnosis and treatment of cancer are usually associated with physical and psychological suffering [1] for both children and their relatives, mainly as a function of the set of factors that determine the quality of life of all of the individuals involved in the process [2]. Such factors include discontinuation of the previous activities of daily life, problems related with treatment and its side effects, and the systemic complications of antineoplastic therapy, which frequently appear at some point during treatment. All of those factors, together with the difficulties involved in access to healthcare, result in patient wear, which has a deep impact on their quality of life [3,4].

The incidence of malignant neoplasms has increased over time, to the point that they currently represent one of the main causes of morbidity and mortality in Brazil and worldwide [5,6]. Similarly, the incidence of childhood cancer, approximately 7,000 new cases per year, represents the second highest proportional mortality ratio among children and adolescents aged one to 19 years in all of the Brazilian regions [7].

Antineoplastic chemotherapy is included in 70% of the cancer treatment protocols, either alone or combined with radiotherapy and/or surgery [8]. Some of the main side effects of antineoplastic treatment are mucositis, nausea, vomiting, xerostomia and loss of taste [9-11]. Mucositis has particularly negative effects on patient quality of life because it affects the ability to eat and speak, nutrition and hygiene [12]. In addition, the condition might lead to the interruption of medical treatment, with pauses in chemotherapy to treat opportunistic infections [13].

The oral health of children with cancer should be properly monitored and treated, while taking into consideration the fact that hospitalization changes their daily routine [14] and causes treatment-related stress. Within that context, care should be provided by an integrated multi-professional staff, including doctors, nurses and dental surgeons, and attention should also be paid to oral health [4,15,16].

As a function of the aforementioned considerations, the aim of the present study was to analyze the access to dental care and the oral health care provided to children aged zero to 19 years who were treated at the Napoleão Laureano Hospital, João Pessoa, Brazil. In particular, we sought to establish the patients' access to the available dental services, the possible difficulties encountered in oral health care, and the main oral health problems associated with treatment, identifying oral health care conceptions based on the meanings given by the patients and/or their caregivers, along with their satisfaction with the oral health care received.

Material and Methods

The present study employed quantitative-qualitative methods, adopting an inductive approach that includes descriptive procedures and an intensive direct observation technique.

The study was conducted at the Napoleão Laureano Hospital, city of João Pessoa, state of Paraíba, which is a reference for the diagnosis and treatment of cancer in the state of Paraíba. The study was approved by the ethics in human research committee of the Lauro Wanderley University

Hospital, protocol no. 259-11. In Napoleão Laureano Hospital, the pediatric unit tends to children and adolescents aged zero to 19 years old; it is located in an annex and consists of an outpatient clinic, where consultations and exams are performed, and an inpatient area with 19 beds distributed across 12 rooms, in addition to an area for recreation and ludic activities. The unit further includes two supporting houses for the children and their relatives, especially for those families who live in the interior of the state, to provide support to them and to improve the quality of life of the patients during their displacements throughout the treatment period.

The study population was represented by all of the patients from both genders aged zero to 19 years who were treated at the hospital from October 2011 to May 2012. The study sample included those who consented or were consented to participate by signing an informed consent form.

After the participants were given the required instructions about the study, data collection was performed by means of a semi-structured interview with open- and closed-ended questions, which was conducted in a private room. Patients older than 12 years old responded to the questions by themselves, while for patients under 12, the interviews were performed with their caregivers. The responses were recorded as MP3 audio files to be fully transcribed at a later time. Two participants refused to have their interviews recorded due to shyness. Therefore, their responses were not recorded but were written down in the data collection instrument.

The transcribed narratives were exhaustively read and analyzed according to the content analysis technique, which allowed establishing six categories: Access to health care services; Physical access to Napoleão Laureano Hospital; Dental care; Participants and/or caregivers' conceptions on oral health care; Quality of life perceptions and health satisfaction; and Health problems derived from anticancer treatment.

The information was analyzed based on Bardin's content analysis technique [17], which includes specific operations to detect themes in texts and then to subdivide them into smaller units; this technique allows identifying the various units of meaning that constitute communication and that can be clustered in different categories. Next, the data were subjected to descriptive analysis using the statistical software IBM SPSS (20.0), which provided measures of central tendency and dispersion and absolute and percent values.

Results

A total of 84 interviews were performed. The sample consisted of 48 (57.1%) males between the ages of two and 18, with a mean age of 10.6 (± 4.2) years. Only 15 (17.8%) patients resided in João Pessoa, where treatment was performed. The remainder of the data is described in Table 1, which indicates the main categories subjected to analysis and the themes related to them.

The narratives transcribed below illustrate the six categories described in Table 1; they are excerpts of the interviews that agree with the various suggested thematic axes.

Table 1: Summary of categories and analyzed thematic axes.

Categories	Thematic Axes
1) Access to healthcare services	A – Ease/difficulty in obtaining general health care. B – Ease/difficulty in obtaining oral health care.
2) Physical access to Napoleão Laureano Hospital	C – Mode of transport from home to the Napoleão Laureano Hospital. D – Travel distance in kilometers. E – Time spent travelling. F – Place where care is provided.
3) Dental care	G - Quality. H - Most frequent reason for care.
4) Patients and/or caregivers' conceptions on oral health care	I – Related to causes of caries and periodontal disease. J – Related to a broader understanding of oral health care. K – Lack of understanding of what "care" means.
5) Perception of quality of life and health satisfaction	L – Satisfaction with one's own quality of life and state of health. M - Dissatisfaction with one's own quality of life and state of health.
6) Health problems derived from anticancer treatment	N - General effects. O - Effects on the oral cavity.

1) Regarding **access to healthcare services**:

A) Only 14 (16.6%) interviewees reported difficulties in obtaining health care as a function of the child's condition, as exemplified by the following narratives:

> *"He had a fever, but she said she could not see my son because he was registered in another service and that it was best to come straight here."*
> *"I met difficulties at both the Family Health Program outpatient clinic and at the school, too much prejudice. I put her in a school quite far from home."*

B) In regard to oral health care professionals, only four (4.8%) interviewees reported difficulties in obtaining access to services as a function of the child's condition; most of the interviewees met no difficulties whatsoever, as the following excerpt shows:

> *"Yeah, just like that… because I took her to the dentist, no problem, he pulled two teeth out."*

Although one interviewee reported some difficulties, they were not due to the child's state of health:

> *"I haven't taken her there for some time, when she's not ill, the stuff there is broken, that's why her teeth are all rotten, 'cause I stopped taking her there."*

2) Regarding **physical access to Napoleão Laureano Hospital**:

C) In regard to the mode of transport from home to the hospital, most interviewees, 34 (40.4%), responded they used cars provided by the corresponding city government:

> *"I come with a car provided by the city government, I call and they send someone to pick me up."*
> *"A car provided by the city government brings us in and takes us back."*

Other modes of transport were also mentioned:

> *"Grandpa drives us in his car."*
> *"I come by bus."*
> *'I rode the Expresso Guanabara [bus] using the free-ride pass."*

D) Only 18 (21.4%) participants were able to answer the question on the distance from home to the hospital in kilometers:

"I don't know."
"I don't know, I've never looked it up."
"Almost 500 km"

E) As the patients came from several different towns, the time spent in travelling from home to the hospital was quite variable:

"30 to 40 minutes."
"If there's no traffic, about three hours."
"6 hours."
"8 hours."
"It depends whether I come by bus or by car; with a car is less than one hour, but two hours with the bus."

3) Regarding **dental care**:

F) Most interviewees, 44 (52.4%), sought care at basic health units, as shown below:

"At the health unit."
"At the health unit close to home."
"At the Family Health Program."

G) Thirty-eight (45.2%) interviewees rated the quality of dental care excellent or good, and 22 (26.1%) as very poor.

"It has to improve… very low quality."
"Terrible."

H) The most frequent reasons to seek dental care were routine visits, 30 (35.7%), and dental problems, 33 (39.3%), as the following excerpts illustrate:

"Just by the look of the teeth, because it bothers me, right?"
"I'd actually go just when I need."
"Just for a check-up."

4) Regarding **patients and/or caregivers' conceptions of oral health care**:

I) A total of 54 (64.2%) interviewees mentioned sweets or poor oral hygiene as causes of caries and periodontal disease; most respondents, 50 (59.6%), considered the association of those factors as determinants for caries and gum disease. One participant also mentioned smoking as a relevant factor for the development of periodontal disease:

"I believe that caries come when you eat candy, a lot of chocolate, don't brush your teeth, which I believe might cause caries and … I don't know much about gum disease, but I believe that smoking."
"Brushing the teeth wrong, right? Eating a lot of sweets… soda."
"I believe that sweets and brushing the teeth wrong, you have to have the right brush."
"Caries is the rest of food that remains in the teeth."
"Not brushing the teeth, no hygiene, right? Not eating well, eating only sweets."
"Not going often to the dentist, not brushing the teeth."

J) Regarding perceptions of oral health care, 38 (45.2%) interviewees' related tooth brushing and oral care with the diet, and some stressed visits to the dentist and the use of dental floss:

"Brushing the teeth at the right times, after the meals, cleanse the tongue always, floss and then brush the teeth again."
"I believe that brushing the teeth, visit the dentist always, apply fluorine, it has to be that."
"Brushing the teeth three times every day, after the meals."
"Not to eat too much junk food, brush the teeth before sleeping, that kind of stuff."
"It's to take care of the most important part of the body."

K) Some interviewees, 30 (35.7%), did not know what oral health care means, as shown below:

"Almost nothing, just because… where I live, there's no dentist at the Family Health Program, there's one, but he doesn't give much orientation, there are no materials… we go there once in a while, but never get to see the dentist and there's no one to explain anything."
"I understand very little, it's… I don't know."
"No, because sometimes you go and open your mouth and you believe it's one thing, but it's another, so better not to tell."
"I understand some stuff, other stuff I don't understand."

5) **Quality of life perception and health satisfaction:**

L) Most interviewees, 59 (70.2%), reported being satisfied or very satisfied with their state of health, and 53 (63.0%) rated their quality of life as good or very good. Examples of responses indicating satisfaction with quality of life and health are provided below:

"By comparison to the way it was before, it's excellent, great!"
"It's good, thank God."
"It's good in spite of treatment, he eats well."
"Satisfied, in spite of the fight against the disease."
"It's been good till now, thank God, right? I'm very satisfied, she's alright."
"My daughter is alive to begin with, I'm not saying that all that, like… I thank God's part in it."

Most participants in the present study, 44 (52.4%), reported seeking care at basic health units, and 59 (70.2%) reported being satisfied with the dental care received. Nevertheless, according to their narratives, the participants in the present study, 33 (39.3%), tended to seek a dentist only in cases of dental problems, while 30 (35.7%) reported attending routine dental visits.

M) Responses indicating dissatisfaction with quality of life and health:

"Bad, right? 'Cause she's sick, getting treated at the hospital, not so good, right? "
"I'll worry until they say it's over."
"Can't be satisfied, 'cause there's always this concern, 'cause the doctor said it can come back."
"I'm not satisfied, having some problems that ought to get better."

6) **Health problems derived from anticancer treatment**:

N) A total of 59 (70.2%) participants reported the following side effects of treatment, in decreasing order of frequency: nausea (n=16; 27.2%); vomiting (n=9; 15.2%); fever (n=8; 13.6%); alopecia (n=7; 11.9%); mucositis (n=6; 10.1%); headache (n=4; 6.7%); pain without indication of site (n=2; 2.5%); stress (n=3; 5.1%); shame, abdominal pain, dry mouth, lack of appetite and dizziness (n=2; 3.4%); and

toothache, sore gums, bad taste in the mouth, bleeding from the mouth and discomfort (n=1; 1.7%). Some examples of narratives in this regard are:

"I wanted to throw up, sometimes I get dizzy."
"Very queasy, fever, and nothing else."
"The vomiting stuff she had once when I gave her a slice of orange, but after that she hasn't been vomiting for a while."
"Independent from the queasiness, which is normal, right? He feels nothing, I ask him, he feels no pain."
"Pain, he had pain."

O) The frequencies of side effects of treatment in the oral cavity only, in decreasing order, were mucositis (10.1%), dry mouth (3.4%), and toothache, sore gums and bleeding from the mouth (1.7%):

"Vomiting, and only in the tongue, it bothers at the end, it bothers a lot."

Discussion

It was observed that only a small percentage of the patients resided in João Pessoa, PB, and most came from the interior of the state; thus, as expected, access to health care services and professionals was difficult. These findings agree with the ones of another study [18], in which the narratives of cancer patients and their relatives/caregivers pointed to the need for families residing in the interior of the state to travel to specialized services, in addition to the difficulties associated with the process of referral among health care units, which account for the delays in actual care delivery. Within that context, unfavorable socioeconomic conditions are associated with less use of dental care services, resulting in poor oral health [19].

The travel from home to specialized treatment services is considered to be one of the main difficulties met by patients and their families, from the time of diagnosis and throughout the treatment, as a large number of visits are usually required [20]. In general, during treatment, patients go to the hospital daily for examinations and to receive anticancer drugs as indicated in the protocols or to treat comorbidities, such as opportunistic infections and inflammation of the mucous membranes.

Geographical accessibility is one of the components of access, as it concerns the relationship between the localization of services and the location of users, including the modes of transport used, the time spent, distance and the cost of travel. Thus, income determines the frequency of use of health care services, and depending on the distance that must be travelled, it might represent a bottleneck with direct influence on the time elapsed from the onset of signs/symptoms to diagnosis, in addition to its impact on the difficulties associated with the performance of treatment [21].

The quality of health care involves a complex set of criteria, including interpersonal aspects, features related with the doctor-patient relationship, the service, suitable and timely care, and control of complications, including the information provided by patients and their relatives [22]. According to the National Cancer Institute of the United States [23], high-quality health care implies adequate and efficient delivery of services to patients, including satisfactory communication, shared decision-making and cultural sensitivity. In turn, poor-quality care might be associated with either neglect or

excessive care, for instance, indication of unnecessary medications and procedures that might pose risks or produce side effects.

As dental caries is a multifactorial disease, in addition to its biological causes, such as diet and hygiene, which were mentioned by most participants, its control also demands improving people's living conditions reducing social inequalities, increasing the family income and the maternal educational level and ensuring that children have access to schooling [24,25].

Concerning to the health satisfaction, most participants reported being satisfied with the dental care received. These findings agree with the ones of another study [26], in which the participants reported being very satisfied with the care provided by the basic health units' staff members as a whole.

Regarding the control of the biological causes of caries, the roles of multi-professional staff members including doctors, nurses and dentists, have particular relevance. The reason for this importance is that the adoption of oral hygiene protocols by a hospital staff contributes to the prevention of oral mucositis and caries, among other oral diseases [26].

In another published study, the most frequent oral complaints reported by caregivers of patients undergoing anticancer treatment were mucositis (75%), dry mouth (25%), burning and toothache (18.75% each), and loss of taste (6.25%). In the present study, the most frequent side effect of chemotherapy in the mouth was mucositis (10.1%), followed by dry mouth (3.4%). Given the particular vulnerability exhibited by children undergoing anticancer treatment, protocols for oral hygiene are highly relevant. Within this context, dentists play a major role as promoters of health education to prevent the occurrence of oral complications that might interfere with quality of life, and even with the patients' global state of health, with the consequent need to interrupt, discontinue or postpone the treatment needed to achieve the remission of tumors [9,27,28].

Based on the complications associated with anticancer treatment, the establishment of educational, preventive and curative strategies targeting oral health before, during and after treatment aimed at the resolution and/or minimization of discomfort and to improve the quality of life of the patients and their relatives has paramount importance. In Brazil as a whole and in the state of Paraíba in particular, there is little information on the state of the oral health of cancer patients and on their access to and use of dental services. Based on the analysis of the narratives and experiences of the participants relative to the investigated topics, the present study was able to detect issues related to dental health in pediatric cancer patients.

Napoleão Laureano Hospital, where the present study was conducted, includes a dental clinic exclusively for children and adolescents undergoing cancer treatment. The relevance of that facility should be noted, based on the difficulties reported by the participants in traveling between their homes and the hospital and the demands inherent to anticancer treatment, whereby patients must spend much time at the hospital for clinical examinations and for the collection of samples for laboratory tests. The patients often need to be admitted to the hospital, sometimes for very long periods of time, depending on their overall state of health and the indicated therapeutic regimen.

All of those factors contribute to increase the length of stay of patients undergoing anticancer treatment at the hospital, which demands a secondary plan of action targeting all other activities and treatments, including dental care. Thus, the presence of a dental clinic with professionals focused on protecting and monitoring patients' oral health significantly decreases the odds of complications of anticancer treatment due to severe odontogenic infections or mucositis [29].

Regarding the methods used in the present study, it should be noted that qualitative research represents a field of subjective analysis. For this reason, investigators should focus on the elements of human subjectivity [30], presenting as limitations the subjectivity of researchers in the interpretation of data and, consequently, in the conclusions as well [31].

Other methodological limitations of the present study derive from the technique used in the interviews, involving the need of some degree of motivation on the part of the interviewees to respond to the questions, a possible lack of understanding the questions or an inability to answer them in an adequate manner, obtainment of false answers, the possible influence of the interviewer on the interviewees, and the influence of the personal opinion of the interviewer on the obtained responses [32].

Among its advantages, qualitative research affords the possibility of a broader interpretation of the data [29]. Thus, it is expected that the present study will contribute to the planning of actions targeting pediatric cancer patients as concerns the improvement of dental care services to provide better care and to enhance their quality of life throughout the course of treatment.

Conclusion

The results showed that the patients who were treated at Napoleão Laureano Hospital did not meet difficulties in the procurement of dental care. Most of the participants travel to the hospital in cars provided by the corresponding city governments and seek dental care at local Family Health Units when needed. The patients/caregivers demonstrated that they understood that the occurrence of caries and periodontal disease is related to consuming cariogenic diets and following poor oral hygiene. Mucositis was the most common treatment-related problem affecting the oral cavity. Finally, the participants reported being satisfied or very satisfied with their health and that their quality of life was good or very good.

The collected data allowed identifying the characteristics of the targeted population relative to their oral health demands and the availability of and satisfaction with dental care services, along with the various difficulties associated with travelling to the reference treatment centers.

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