

Health Education: Development and Validation of a Guideline for Oral Hygiene of Children Undergoing Cancer Treatment

Educación en Salud: Desarrollo y Validación de una Guía para la Higiene Oral de Niños en Tratamiento Oncológico

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ABSTRACT: Children with cancer commonly present oral health impairments due to lack of orientation about oral hygiene, which should be directed to caregivers since they are essential in this process. We developed and validated a guideline directed to caregivers for oral hygiene of children with cancer. This exploratory methodological study developed an educational guideline in three stages: analysis of oral health of children attended at the oncology service; literature review and development of the guideline for oral hygiene; semantic, appearance, and content validation by dentists, education professionals, and the target population. We used the Educational Content Validation Instrument in Health, and agreements of $\geq 80\%$ among evaluators were considered to maintain or modify the assessed items. Professionals and caregivers were mostly female; the latter were predominantly mothers with low educational level from inland areas of Pernambuco state (Brazil). Most professionals had more than ten years of experience in pediatric dentistry. Agreement was $> 80\%$ in all items. The content of the guideline for oral hygiene was valid and relevant to be used in children with cancer.

KEY WORDS: oncology, education and dissemination materials, oral health education.

INTRODUCTION

Although childhood cancer is the third cause of death in children and adolescents, about 70 % of early diagnosed cases can be cured when treated in specialized centers (Rodrigues & Camargo, 2003). Cancer causes suffering and pain in the affected patients; thus, a multidisciplinary approach is essential to ensure a better quality of life, reduce acute and late complications, and increase the chance of cure (Brasil, 2009; Sociedade Brasileira de Pediatria, 2017; Brasil, 2017).

Cancer treatment, especially chemotherapy, impairs the oral cavity due to direct and indirect stomatotoxicity. Most patients under cancer treatment also present oral mucositis and opportunistic infections due to immunosuppression. In this context, the dentist

must help manage and prevent these complications through laser therapy and orientations regarding oral hygiene (Toassi & Petry, 2002; Hespanhol *et al.*, 2010; Pires *et al.*, 2014).

The oral biofilm is a determining agent in oral diseases (e.g., dental caries and periodontal diseases) and may cause systemic complications in children under cancer treatment. Although mechanical and chemical procedures may control these microorganisms, they are often neglected due to lack of knowledge or adequate orientation (Silva *et al.*, 2011).

Self-care orientations in health education should be performed using simple or advanced technologies.

In this context, health education aims to sensitize, inform, and change risk behaviors that may interfere with individual and collective health (Ministério da Saúde, 2009; Salci *et al.*, 2013). Therefore, educational materials that motivate and educate patients and caregivers are one of the most efficient approaches to changing habits in oral hygiene.

Printed educational materials may help reinforce verbal information and understand oral hygiene (Theis & Johnson, 1995; Buck, 1998; Mialhe & Silva, 2008). These materials are a safe source of information, may clarify doubts at any moment, and stimulate the memory since verbal information during attendance is easily forgotten in a short period (Allen Lapointe *et al.*, 2007).

The validation process is essential to ensure that objectives were achieved during the development of printed materials, allowing them to be recognized and used in health education (Moura *et al.*, 2008; Oliveira *et al.*, 2014). This process also allows verifying the quality of information and its use by the health service, helping in the care and educational role of health professionals (Dodt *et al.*, 2012).

In this context, care with oral hygiene and prevention of oral and systemic infections are essential to improve the quality of life of children under cancer treatment. Therefore, this study aimed to develop and validate a guideline for caregivers regarding oral hygiene of children with cancer. We believe this guideline will support the oral health education of this population.

MATERIAL AND METHOD

This exploratory methodological study was conducted from November 2020 to January 2022 in three stages: assessment of oral health of children attended at the oncology service; literature review and development of a guideline for oral hygiene directed to caregivers and containing relevant oral health information during cancer treatment; and semantic, appearance, and content validation by dentists, education professionals, and the target population.

The Educational Content Validation Instrument in Health (ECVIH) was adapted to analyze and validate the guideline (Leite *et al.*, 2018). The ECVIH is divided into three domains: objectives (purposes, goals, or finalities), structure/presentation (organization,

structure, strategy, coherence, and sufficiency), and relevance (significance, impact, motivation, and interest) of educational materials. This tool measures the agreement rate in each domain. Responses are provided using a 3-point Likert scale (totally disagree, 0; partially agree, 1; and totally agree, 2) (Leite *et al.*, 2018), and descriptive criticisms and suggestions can be provided to develop the final version of the assessed material.

In the first stage, a pilot study was developed by reviewing dental records and establishing the oral health condition of children attended at the oncology service. During cancer treatment, children presented many dental caries and teeth requiring pulp therapy, indicated for extraction, or extracted due to a focus of infection. Considering the impaired oral health of these children, we decided to develop an educational material for caregivers to inform the importance of oral treatment and care.

The second stage focused on developing the guideline. A literature review was conducted on the main adverse effects of cancer treatment in the oral cavity of children. The guideline text was clearly and concisely developed and covered the prevention of dental caries and oral hygiene in cases of oral changes (e.g., mucositis) during cancer treatment. Eight professionals evaluated the text and suggested the content and sequence of information in the material. After validation, a designer drew attractive and easy-to-understand illustrations based on the cultural context of the target population. Next, an advertising professional structured the guideline information to ensure harmony and visual acceptance.

The third stage started after finishing the guideline. A total of 21 dentists, 3 education professionals, and 66 caregivers assessed the guideline. The assessment occurred in person and virtually due to the COVID-19 pandemic. Dentists who worked in the health service and education professionals responded to the items of the ECVIH in person, whereas those from other services responded virtually using the Google Forms. All caregivers responded in person while waiting for the children to be attended at the oncology outpatient or nursery.

We included professionals working with pediatric or hospital dentistry (at least one year of experience) and health education (at least two years of experience). The outcome years of experience was classified into three groups (< 5; 5 to 10; and > 10 years).

Professionals who were away due to work reasons (e.g., vacation, license, or medical certificate) during the assessment period or did not respond to the invitation to participate in the study were excluded.

The inclusion of caregivers was based on the following criteria: age over 18 years, kinship or legal responsibility with the child, regularly living with the child outside the hospital environment, participating in the oral hygiene of the child, and knowing about the diagnosis and time of cancer treatment. Those who could not read the material were excluded. Caregivers were categorized into three living regions: metropolitan region of Recife city (Pernambuco, Brazil), inland areas of the Pernambuco state, and another state. They were also grouped according to educational levels (≤ 8 ; between 9 and 11; and ≥ 12 years).

Data were categorized and tabulated using an Excel® spreadsheet and analyzed using the Stata® 13.0 software. Significance level was set at 95 %, while an agreement (partial and total) level of 80 % among assessors was used as criterion to maintain or modify the assessed items.

The study followed the Declaration of Helsinki and was approved by the research ethics committee of the Instituto de Medicina Integral Prof. Fernando Figueira – IMIP (CAEE no. 49998121.0.0000.5201). Professionals and caregivers who assessed the guideline were informed about the study aims and data collection and signed the informed consent form.

RESULTS

Results were presented in two topics: development of the guideline and validation process.

Development of the guideline. A summary was developed with the main information from scientific articles and guidelines on oral health. The following questions were formulated for the guideline: (1) “when should the first visit to the dentist occur?”; (2) “when should I start cleaning the mouth of the child?”; (3) “how should the oral hygiene of the child be performed?”; (4) “which dentifrice should be used?”; (5) “which toothbrush should be used?”; (6) “should children brush their teeth alone?”; and (7) “why should I be careful with the oral health of the child?”

Information about routine situations in oncology was also included (e.g., thrombocytopenia, mucositis, and candidiasis). Moreover, a call with the sentence “saw something, say something” was included in case caregivers noticed unusual changes in the mouth of children. This sentence advised the importance of informing changes in the oral health of children for immediate assessment and treatment.

The guideline adopted an accessible language to all educational levels and was designed to combine the content with consistent and objective information. Information was also summarized to facilitate the understanding of the target population. The guideline was developed in one A4 size paper with two-sided information divided into six parts. The preliminary version of the guideline was printed for the validation process using the ECVIH. After validation and adjustments, the final version was entitled “Guia de orientação sobre saúde e higiene bucal” (Guideline on oral health and hygiene). Figures 1 and 2 shows the front and back sides of the guideline.



Fig. 1. Front side of the "Guia de orientação sobre saúde e higiene bucal".



Fig. 2. Back side of the "Guia de orientação sobre saúde e higiene bucal".

Validation of the guideline. Specialist professionals in pediatric and hospital dentistry, education professionals, and caregivers assessed the guideline. Most professionals were females (95.0 %) aged 27 to 59 years (median of 40 years). Nine (42.8 %) dentists had specialization or residency, and six (28.6 %) were Ph.D. Most professionals (70.8 %) had five or more years of experience in education or dentistry, while all education professionals had experience elaborating educational materials in the health area. Table I shows the agreement among professionals according to the ECVIH.

Caregivers were mostly females (90.9 %) aged 21 to 63 years (median of 34.5 years). Most caregivers were from the inland areas of Pernambuco state (60.6 %), 33.3 % lived in the metropolitan region of Recife city, and 6.1 % were from another state. Regarding educational level, 27.3 % had < 8 years of study, 54.6 % had between 9 and 11 years, and 18.2 % had \geq 12 years of study. Caregivers judged the guideline adequate, and agreement was > 80 % in all ECVIH items (Table II).

Participants were asked how the guideline should be disseminated (i.e., printed, virtually, or both). Most caregivers (68.2 %) chose the printed version, whereas 41.7 % of professionals chose both versions for dissemination.

DISCUSSION

The guideline developed in the present study was validated as educational material for caregivers, offering credibility in the care of children attended at the oncology service. This guideline reinforced the importance of hygiene in oral cavity care, especially during cancer treatment. A study that developed a guideline for patients submitted to head and neck radiotherapy increased knowledge dissemination and helped the target population to better understand information (Cruz *et al.*, 2016). According to the validation process, the present guideline was a relevant and valid educational material for oral health and hygiene.

Table I. Agreement among professionals according to domains of the ECVIH.

ECVIH Items	PROFESSIONALS															
	DENTISTS								EDUCATORS							
	TD*		PA		TA		A (total)		TD		PA		TA		A (total)	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
OBJECTIVES																
Contemplate the proposed topic	-		2	10	19	90	21	100	-				3	100	3	100
Adequate for the teaching-learning process	-		1	5	20	95	21	100	-				3	100	3	100
Clarify doubts about the addressed topic	-		5	24	16	76	21	100	-				3	100	3	100
Provide reflection on the topic	-		3	14	18	86	21	100	-	1	33	2	67	3	100	
Encourage behavior change	-		5	24	16	76	21	100	-				3	100	3	100
STRUCTURE/PRESENTATION																
Adequate language for the target population	-		5	24	16	76	21	100	-				3	100	3	100
Adequate language for educational material	-		4	19	17	81	21	100	-				3	100	3	100
Interactive language, enabling active involvement in the educational process	-		4	19	17	81	21	100	-	1	33	2	67	3	100	
Correct information	-		3	14	18	86	21	100	-				3	100	3	100
Objective information	-		2	10	19	90	21	100	-				3	100	3	100
Clarifying information	-		4	19	17	81	21	100	-				3	100	3	100
Needed information	-				21	100	21	100	-				3	100	3	100
Logical sequence of ideas	-		2	10	19	90	21	100	-				3	100	3	100
Current topic	-				21	100	21	100	-				3	100	3	100
Adequate text size	1	5	1	5	19	90	20	95	-				3	100	3	100
RELEVANCE																
Stimulate learning	-		5	24	16	76	21	100	-	1	33	2	67	3	100	
Contribute to knowledge in the area	-				21	100	21	100	-				3	100	3	100
Arouse interest in the topic	-		1	5	20	95	21	100	-				3	100	3	100

Data presented as absolute (N) and relative frequency (%). ECVIH = Educational Content Validation Instrument in Health; TD = totally disagree; PA = partially agree; TA = totally agree; A = partial and total agreement.

Table II. Agreement among caregivers in the assessment of the “Guia de orientação sobre saúde e higiene bucal” according to domains of the ECVIH.

ECVIH Items	CAREGIVERS									
	TD		PA		TA		A (total)			
	N	(%)	N	(%)	N	(%)	N	(%)		
OBJECTIVES										
Clarify doubts about the addressed topic	4	6	12	18	50	76	62	94		
Provide reflection on the topic	4	6	13	20	49	74	62	94		
Encourage behavior change	10	15	9	14	47	71	66	85		
STRUCTURE/PRESENTATION										
Adequate language for educational material	2	3	3	5	61	92	64	97		
Objective information	1	1	6	9	59	90	65	99		
Clarifying information	1	1	6	9	59	90	65	99		
Needed information			3	5	63	95	66	100		
Adequate text size	3	4	5	8	58	88	63	96		
RELEVANCE										
Stimulate learning	-		2	3	64	97	66	100		
Contribute to knowledge in the area	-		5	8	61	92	66	100		
Arouse interest in the topic	-		4	6	62	94	66	100		

Data presented as absolute (N) and relative frequency (%). ECVIH = Educational Content Validation Instrument in Health; TD = totally disagree; PA = partially agree; TA = totally agree; A = partial and total agreement.

The ECVIH was created and tested in Brazil to validate the content of educational materials for health education. As an advantage, the domains of this tool do not focus on specific topics or populations (Leite *et al.*, 2018). The objectives domain of the ECVIH, for example, allows understanding the addressed topic according to purposes, goals, or finalities (Antoniolli *et al.*, 2021). All items had > 80 % agreement among assessors, suggesting an adequate guideline.

Educational material must be clearly written and organized with adequate language to transmit accurate information to the target population (Oliveira *et al.*, 2014; Coluci *et al.*, 2015; Galindo-Neto *et al.*, 2019). Therefore, health professionals should use adequate tools to facilitate the development and validation of these materials for patients and their families (Áfio *et al.*, 2014).

The structure/presentation domain of the ECVIH assessed the organization, structure, strategy, coherence, and sufficiency of the guideline (Leite *et al.*, 2018; Antoniolli *et al.*, 2021). Although items were similar for professionals and caregivers, the latter responded to a summarized version. A study reported that assessing the structure/presentation domain during the development and validation of guidelines might avoid misinterpretation of the content by the target population (Ribeiro *et al.*, 2017).

During the validation of a guideline for accessibility and inclusion of students with disabilities in basic education using the ECVIH, the agreement between judges ranged from 55.6 % to 100 % in the structure/presentation domain (Lima, 2019). Although the guideline also obtained an acceptable agreement rate in the other domains of the ECVIH, researchers reassessed and revalidated it until obtaining maximum scores in all items of the final version (Lima, 2019). Moreover, researchers reported the non-participation of the target population as a limitation in the validation process (Lima, 2019). In our study, professionals and caregivers obtained > 95 % agreement on almost all items, except for the text size among dentists. Although the agreement was satisfactory, the text size was readjusted for the final version according to suggestions.

The relevance domain of the ECVIH assessed the significance, impact, motivation, and interest. According to this domain, the social context, needs, and specificities of the target population must be known to ensure a satisfactory content in the guideline (Leite

et al., 2018). Promoting reflection and encouraging behavior change is essential to achieve the objectives of the educational material; thus, becoming a reflective, critical, and attitudinal technology (Gentil *et al.*, 2017; Lima, 2019). The agreement among assessors in this domain was 100 %.

Educational materials must be developed and validated using methodological and scientific rigor to become reliable, suitable, and effective for the target population (Oliveira *et al.*, 2014; Medeiros *et al.*, 2015). In the health area, these educational materials allow the interaction between specific technical knowledge of professionals and experiential knowledge of the target population (Magalhães, 2014), reinforcing information mentioned during routine attendance. Moreover, these materials facilitate health education, reinforce oral information, clarify doubts, help decision-making, and allow readers to obtain and expand their knowledge (Assis *et al.*, 2013). Although our guideline may help with oral health and hygiene needs during and after the cancer treatment, it does not replace the verbal recommendations of professionals during in-person attendance (Padilha *et al.*, 2017).

The limitations of this study include the small number of professionals specialized in pediatric or hospital dentistry working with children during cancer treatment and education professionals with experience validating educational materials. The validation by the target population was advantageous since it verified and improved the understanding of information in the guideline. Nevertheless, the content should be further reviewed due to changes in protocols for treating health conditions and the publication of new studies presenting different perspectives on the approach of these patients.

The final version of the guideline was entitled "Guia de orientação sobre saúde e higiene bucal". This guideline was developed and validated according to previous studies in the area. Professionals and caregivers contributed significantly to validating the final version of the guideline. Moreover, the language used in the guideline was valid and adequate for the health education process of caregivers. Further studies on the topic should be conducted due to its importance for health practice, especially for professionals concerned with guiding and providing simple tools to caregivers and improving oral health care and self-care autonomy of children undergoing cancer treatment.

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RESUMEN: Los niños con cáncer comúnmente presentan afecciones en la salud bucal por falta de orientación sobre la higiene bucal, la cual debe ser dirigida a los cuidadores ya que son fundamentales en este proceso. Desarrollamos y validamos una guía dirigida a cuidadores para la higiene bucal de niños con cáncer. Este estudio metodológico exploratorio desarrolló una directriz educativa en tres etapas: análisis de la salud bucal de los niños atendidos en el servicio de oncología; revisión de la literatura y desarrollo de la guía para la higiene oral; validación semántica, de apariencia y de contenido por parte de odontólogos, profesionales de la educación y población objetivo. Se utilizó el Instrumento de Validación de Contenido Educativo en Salud, y se consideraron acuerdos $\geq 80\%$ entre evaluadores para mantener o modificar los ítems evaluados. Los profesionales y cuidadores eran en su mayoría mujeres; estas últimas eran predominantemente madres con bajo nivel educativo del interior del estado de Pernambuco (Brasil). La mayoría de los profesionales tenían más de diez años de experiencia en odontopediatría. La concordancia fue $> 80\%$ en todos los ítems. El contenido de la guía de higiene oral fue válido y pertinente para ser utilizado en niños con cáncer.

PALABRAS CLAVE: oncología, materiales de educación y difusión, educación en salud oral.

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