

# The ABC of Cancer Guide: Validation of an Educational Book for Children, Families, and Healthcare Professionals

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*Guia Beabá do Câncer: Validação de Livro Educativo para Crianças, Famílias e Profissionais de Saúde*

*Guía De la A a la Z del Cáncer: Validación de un Libro Educativo para Niños, Familias y Profesionales de la Salud*

Simone Lehwess Mozzilli<sup>1</sup>; Pedro Emilio Gomes Prates<sup>2</sup>; Isadora Cardoso Salles Fila Pecenin<sup>3</sup>;  
Lucas Thiago Pereira da Silva<sup>4</sup>; Marina de Góes Salvetti<sup>5</sup>

## ABSTRACT

**Introduction:** The diagnosis of childhood cancer brings fear, distress, and suffering to patients and their families, negatively impacting communication and treatment adherence. Validated educational materials can improve understanding and active participation in care. **Objective:** To validate the content of the educational book “The ABC of Cancer Guide” from the perspective of children, adolescents, families, and healthcare professionals. **Method:** Methodological study of content validation using the Suitability Assessment of Materials (SAM) method to evaluate material adequacy in six categories (content, language, illustration, presentation, motivation, and cultural adaptation) and indicators of user’s experience. Data were collected virtually via Adobe Sign and analyzed with the software Statistical Package for the Social Sciences (SPSS), applying indicators as clarity, vocabulary, attractiveness, and usability. **Results:** The study enrolled 12 children and adolescents, 20 family members, and 29 healthcare professionals. The material was validated with scores of 100% by children and adolescents, 98.4% by family members, and 97.6% by healthcare professionals, exceeding the minimum scores of 40% and 60% required to rate the material as adequate or superior. Suggestions for improvement of clarity and vocabulary were made, particularly for audiences with lower health literacy. **Conclusion:** “The ABC of Cancer Guide” was validated as an appropriate tool for health education for children undergoing cancer treatment and their families. Future studies are recommended to evaluate the guide’s impact on clinical practice and improvement of treatment adherence.

**Key words:** Pediatrics; Health Education; Teaching Materials; Treatment Adherence and Compliance; Child Health.

## RESUMO

**Introdução:** O diagnóstico de câncer infantil gera medo, angústia e sofrimento para pacientes e suas famílias, impactando negativamente a comunicação e a adesão ao tratamento. Materiais educativos validados podem melhorar a compreensão e a participação ativa no cuidado. **Objetivo:** Validar o conteúdo do livro educativo “Guia Beabá do Câncer” sob a perspectiva de crianças, adolescentes, famílias e profissionais da saúde. **Método:** Estudo metodológico de validação de conteúdo utilizando o método *Suitability Assessment of Materials* (SAM) para avaliar a adequação do material em seis categorias (conteúdo, linguagem, ilustração, apresentação, motivação e adaptação cultural) e indicadores da experiência do usuário. Os dados foram coletados virtualmente, via *Adobe Sign*, e analisados no *software Statistical Package for the Social Sciences* (SPSS), utilizando-se indicadores como clareza, vocabulário, atratividade e usabilidade. **Resultados:** Participaram do estudo 12 crianças e adolescentes, 20 familiares e 29 profissionais da saúde. O material foi validado com escores de 100% pelas crianças e adolescentes, 98,4% pelos familiares e 97,6% pelos profissionais de saúde, superando os escores mínimos de 40% e 60%, necessários para considerar o material adequado ou superior ao adequado. Foram feitas sugestões de melhorias nas áreas de clareza e vocabulário, especialmente para públicos com menor letramento em saúde. **Conclusão:** O “Guia Beabá do Câncer” foi validado como uma ferramenta adequada para a educação em saúde de crianças em tratamento oncológico e seus familiares. Estudos futuros são recomendados para avaliar o impacto do guia na prática clínica e na melhoria da adesão ao tratamento.

**Palavras-chave:** Pediatria; Educação em Saúde; Materiais de Ensino; Cooperação e Adesão ao Tratamento; Saúde da Criança.

## RESUMEN

**Introducción:** El diagnóstico de cáncer infantil genera miedo, angustia y sufrimiento para los pacientes y sus familias, impactando negativamente en la comunicación y la adhesión al tratamiento. Los materiales educativos validados pueden mejorar la comprensión y la participación más activa en el cuidado. **Objetivo:** Validar el contenido del libro educativo “Guía de la A a la Z del Cáncer” desde la perspectiva de niños, adolescentes, familias y profesionales de la salud. **Método:** Estudio metodológico de validación de contenido utilizando el método *Suitability Assessment of Materials* (SAM) para evaluar la adecuación del material en seis categorías (contenido, lenguaje, ilustración, presentación, motivación y adaptación cultural) e indicadores de la experiencia del usuario. Los datos se recopilaron de forma virtual a través de *Adobe Sign* y se analizaron con el *software Statistical Package for the Social Sciences* (SPSS), utilizando indicadores como claridad, vocabulario, atractivo y usabilidad. **Resultados:** En el estudio participaron 12 niños y adolescentes, 20 familiares y 29 profesionales de la salud. El material fue validado con puntuaciones del 100% por niños y adolescentes, 98,4% por familiares y 97,6% por profesionales de la salud, superando los puntajes mínimos de 40% y 60% necesarios para considerar el material adecuado o superiormente adecuado. Se realizaron sugerencias de mejora en las áreas de claridad y vocabulario, especialmente para públicos con menor alfabetización en salud. **Conclusión:** La “Guía de la A a la Z del Cáncer” fue validada como una herramienta adecuada para la educación en salud de niños en tratamiento oncológico y sus familias. Se recomiendan futuros estudios para evaluar el impacto de la guía en la práctica clínica y en la mejora de la adherencia al tratamiento.

**Palabras clave:** Pediatría; Educación en Salud; Materiales de Enseñanza; Cumplimiento y Adherencia al Tratamiento; Salud Infantil.

<sup>1,3</sup>Universidade de São Paulo (USP), Escola de Enfermagem. São Paulo (SP), Brasil. E-mails: [simone@beaba.org](mailto:simone@beaba.org); [isadoracsalles@gmail.com](mailto:isadoracsalles@gmail.com). Orcid iD: <https://orcid.org/0000-0002-9242-2889>; Orcid iD: <https://orcid.org/0009-0003-7705-6870>

<sup>2</sup>USP, Escola de Enfermagem de Ribeirão Preto (EERP-USP). Ribeirão Preto (SP), Brasil. E-mail: [pedropratesmoreno@usp.br](mailto:pedropratesmoreno@usp.br). Orcid iD: <https://orcid.org/0000-0002-4920-7649>

<sup>4</sup>USP, Programa Interunidades de Doutorado em Enfermagem. São Paulo (SP), Brasil. E-mail: [lucasthiago@usp.br](mailto:lucasthiago@usp.br). Orcid iD: <https://orcid.org/0000-0001-5496-3652>

<sup>5</sup>USP, Departamento de Enfermagem Médico-Cirúrgica. São Paulo (SP), Brasil. E-mail: [mgsalveti@usp.br](mailto:mgsalveti@usp.br). Orcid iD: <https://orcid.org/0000-0002-4274-8709>

**Corresponding author:** Pedro Emilio Gomes Prates. EERP-USP. Rua Professor Hélio Lourenço, 3900 – Vila Monte Alegre. Ribeirão Preto (SP), Brasil. CEP 14040-902. E-mail: [pedropratesmoreno@usp.br](mailto:pedropratesmoreno@usp.br)



## INTRODUCTION

Childhood cancer is a harrowing experience for patients and families, usually imbued with feelings of fear, suffering and uncertainties, aggravated by multiple prognosis and available therapeutic options that can create a perception of impotence<sup>1,2</sup>. Although the advances have significantly increased the rates of cure, especially with early diagnosis, the treatment continues to be long and challenging, with exams, medical visits and hospital admissions. In many cases, children are excluded from the processes of communication about the diagnosis and treatment related decisions usually conducted by health professionals and family<sup>3</sup>.

Clear and proper information matched to the cognitive and emotional needs of children and their families are essential to manage the uncertainties and minimize the stress and anxiety the oncologic treatment creates<sup>4</sup>. Shared decision-making with children about the plan of care, respecting their level of cognitive maturity can improve the understanding about the treatment and care received<sup>5</sup>. Health literacy plays a key role while providing accurate information about the diagnosis, procedures and treatments, helping to mitigate the anguishes in the course of the disease<sup>6,7</sup>.

Systematic reviews indicate continuous demand for easy-to-understand and clear information for relatives of children in oncologic treatment. These families need comprehensive data about the treatment, medications, how to cope with the disease and support available, regardless of their level of health literacy<sup>8</sup>. The lack of validated educational materials can lead to inadequate information, compromising the adherence to the treatment and effective management of the disease.

“The ABC of Cancer: a quick guide of what you need to know about cancer” was developed to fill these communication gaps, utilizing principles of visual communication and advertising to create an accessible material for children, adolescents and relatives. Consisting of more than 100 common terms of the oncologic environment and cost-free, the guide aims to demystify cancer and its treatment, providing quality information in a simple and visual language<sup>9</sup>. Nevertheless, despite its wide acceptance and use, the guide was not formally validated yet, which limits its performance as educative tool.

Validate educative materials as “The ABC of Cancer Guide” is essential to ensure they meet the informative and emotional needs of the target-public, promoting appropriate communication among the health team and patients, and encouraging self-care<sup>10</sup>.

The present study has the objective of validating the content of “The ABC of Cancer Guide” in the

perspective of children, adolescents, families and health professionals. The validation attempts to not only improve the quality of the information for this vulnerable public but also stimulates the adherence to the treatment and selfcare contributing to the well-being of cancer pediatric patients.

## METHOD

Methodological study of validation of the content of the educative material “The ABC of Cancer: a rapid guide of what you need to know about cancer”. The validation of the content is an essential process to ensure the material is relevant, understandable and proper to the target-public, meeting the established quality criteria. The development of the material occurred between 2013 and 2015, following good clinical practices described in Project Management Body of Knowledge (PMBOK) and utilizing the framework Scrum. The PMBOK provided the formal structure to manage the project comprehending the initiation, planning, execution, control and closure, while Scrum allowed an agile and interactive approach, facilitating the continuous collaboration and feedback among the development teams, which is pivotal to create educative responsive materials to user’s needs<sup>9</sup>.

The creation of the educative material was driven by the principles of cocreation and interdisciplinarity, involving the active participation of children and adolescents in oncologic treatment, families, health professionals and experts in information technology and communication. The selection of the participants was based on direct and complementary experiences. Regular meetings and collaborative workshops have been conducted to ensure the material was inclusive and relevant to all users<sup>9</sup>.

The development process followed the steps: :

- **Categorize and tag the terms:** Identification and categorization of more than 100 terms common to the oncologic environment to be included in the guide.
- **Create collaborative environment:** Establishment of a Google Drive-based collaborative working environment to facilitate the insertion and revision of the terms by the team members.
- **Validation and description of the terms:** Revision and validation of the terms by health professionals to ensure accuracy and relevance.
- **Definition of style and suitability of the language:** Development of an accessible and involving writing style matched to children and adolescents.
- **Production of a mockup and final approval:** Creation of a mockup of the guide for evaluation and final adjustments prior to its production.

The recommendations of the EQUATOR network Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)<sup>11</sup> guided the strict and systematic reporting of all the process stages, ensuring transparency and reproducibility.

The study population consisted of children and adolescents who experienced oncologic disease in infancy or youth, their families and health professionals. The sample by convenience included children, adolescents and young adults, their families and health professional who utilized the educative book “The ABC of Cancer Guide” during oncologic treatment.

Young adults were enrolled in the study because they used “The ABC of Cancer Guide” while they were adolescents. This decision aimed to address the retrospective experience of these individuals with the educative material, considering that at enrollment, they were no longer at the age range formally defined as adolescence but that could contribute with relevant information related to the use of the guide in that phase. This approach allowed to evaluate the application of the material in a specific period of the life it was utilized without compromising the coherence of the study focused to children and adolescents.

Inclusion criteria were: children aged or older than four years of age, adolescents and young adults in oncologic treatment, follow-up, partial or total disease remission who utilized the educative book “The ABC of Cancer Guide” previously, as well as their relatives or companions and health professionals who had utilized the book. Those who did not use the Guide during the treatment were excluded.

Potential participants were enrolled through snowball sampling, a common quantitative method with good performance in nursing-related researches<sup>12</sup>. The participants of the initial sample were identified and enrolled through contact network of the investigators involved and partner hospitals who referred other potential participants, and so on, with the participants indicating other eligible individuals until the final sample was reached. The inclusion criteria were checked through all the stages, and if the participants met this condition, they were invited to join the study through an invitation letter. At the initial approach, it was confirmed whether the participants had ever been in contact with the book and it was offered them a reliable digital version for their knowledge.

The invitations were distributed through the contact network of the study group, social media and organizations dedicated to healthcare to children with cancer and their families. The sample by convenience consisted in individuals who accepted to join and signed

the Informed Consent Form (ICF) through the platform Adobe Sign, after receiving all the required information and according to ethical principles for studies with human beings.

Authorization for children’s participation in the study were asked to the responsible or legal guardians, by signing the respective informed consent form (ICF) and assent form (AF) signed by the children. The investigators provided clarification to the participants through a Google Meet video call adjusted to the children, families or health professionals schedule prior to signing the ICF and AF.

Data were collected virtually due to COVID-19 restrictions from June to November 2020, through a questionnaire constructed with the software Typeform<sup>13</sup>. The indicators utilized to validate the material were based on the method Suitability Assessment of Materials (SAM)<sup>14</sup>, translated and validated to the Brazilian context by Sousa, Turrini and Poveda<sup>15</sup>. This instrument evaluated the suitability of the educative materials in six categories: content, language, illustration, presentation, motivation and cultural adaptation<sup>16</sup>.

Additionally, the collection instrument included socioeconomic and clinical variables to characterize the sample and contextualize the results. Sex, age range, region of birth, education, type of cancer of children and adolescents were collected and phase of the treatment when they received “The ABC of Cancer Guide”, number of treatments performed and duration of the last treatment. These variables allowed a more detailed analysis of the participants perceptions about the educative material, contributing to the robustness of the results.

The participants responded to the instrument SAM applied in the version validated to Brazil. This approach offers a systematic method to evaluate objectively the suitability of the material as an informative health product with structured criteria and adjusted to the national context<sup>14,15,17</sup>. Each category evaluated included specific questions related to the objective, clarity and accessibility of the content, in addition to aspects as interaction and involvement of the users<sup>14,15,17</sup>.

In addition, the evaluation with the target public occurred through validated SAM<sup>15</sup>, ensuring that the instrument applied was appropriate to measure the suitability to the proposed target public. Organization of the didactic resource, language, appearance (including illustrations and layout) and motivation were evaluated. For each indicator, the participants marked one of the options: “agree” (2 points), “partially agree” (1 point) or “disagree” (0 points), according to SAM’s methodological criteria.



Within each category, the questions were adjusted to address the needs of the specific public. Special care was taken for children and adolescents with concrete and objective questions while for adults (families and health professionals) the questions were more comprehensive. Parents or legal guardians helped their children to complete the instrument, considering the level of literacy of each participant, allowing the adults to read when necessary. In addition, the study team scheduled Google Meet video calls to the participants availability to offer support while completing the questionnaire (Chart 1).

The software Statistical Package for the Social Sciences (SPSS)<sup>18</sup> was utilized to consolidate and organize the data collected with the instrument, the responses were digitalized and the variables considered for validation were content, language, presentation and experience of the user, analyzed with specific markers. Descriptive analysis was performed to summarize the main characteristics of the variables, with absolute and relative frequencies and measures of central tendency to describe sociodemographic, clinical data and scores of validation.

The content was analyzed in relation to purpose, organization and reliability. The language was analyzed for clarity, style and vocabulary, the presentation, for layout, images and typography and the user experience, in regard to attractiveness, interaction, involvement and usability.

For the calculation of the total score, according to the methodology SAM, the score obtained for all the items was summed and the result reached was converted in percent of the total score (maximum possible) between 0% and 100%. The scores are interpreted as follows: 70%-100%, superior material, 40%-69%, adequate material and 0%-39%, non-suitable material<sup>15</sup>. The participants were divided in three groups to analyze the data: 1) children and adolescents, 2) family and companions and 3) health professionals with the results presented descriptively.

The Ethics Committee of “*Escola de Enfermagem da Universidade de São Paulo (EEUSP)*” approved the study, report number 3,890,583 (CAAE (submission for ethical review): 26095019.0.0000.5392) in compliance with Directive 466/2012<sup>19</sup> of the National Health Council. Safe platforms to collect and store the information were utilized to ensure the protection of the participants information according to the guidelines of the Brazilian General Data of Protection Law (GDPL) and of the National Ethics Committee (CONEP).

## RESULTS

12 children and adolescents/young adults, 20 relatives and companions and 29 health professionals joined the study. Young adults who utilized the guide previously

as children or adolescents were included in that group. The group age ranged from 5 to 12 years old with mean age of 14.4 and median of 15 years. A considerable part of the sample of this group was formed by adolescents and young adults survivors of childhood cancer (Table 1).

The most common types of cancer were leukemia (33.0%) and lymphoma (33.0%), followed by neuroblastoma (25.0%). “The ABC of Cancer Guide” was received mostly during treatment (33%) and follow-up (33%), with 83% of the participants receiving the book in their first treatment (Table 1).

The educative book “The ABC of Cancer Guide” was validated by the group of children and adolescents with mean final score of 100%, reflecting their concurrence with all the items evaluated and did not present critiques or suggestions to improve the content, language, presentation and analysis of the experience.

The group of relatives and companions was formed by 20 participants, with predominance of mothers (85.0%), with complete high-school (55.0%), in the age range of 31-45 years, birth origin in the Southeast region (75.0%), with no previous knowledge of oncology (Table 2).

The book was validated by relatives and companions with a final score of 25.6, accounting for 98.4% of the maximum total score. All the participants concurred with the indicators of content and presentation, one participant disagreed with the style and other suggested to improve the attractiveness, interaction and usability (Chart 2).

Of the health professionals, 29 were mostly women (90%), aged 25-51 years, with mean age of 37 and median of 35.5 years. The Southeast region was the birth origin of 69% of the participants, 17% from the South, 7% from the Midwest and 3.5% from the Northeast regions and one was Chilean (3.5%).

The group was formed by different professionals as oncologists, nurses, licensed nurse practitioners, psychiatrists, psychologists, pedagogists, social workers, occupational therapists, speech therapists, nutritionists, pharmacists, physiotherapists, integrative health practitioners, palliativists, information technology and communication professionals as project managers, information architects, writers, illustrators, art directors, reviewers and graphic producers. The multidisciplinary composition reflects the diversity of the perspectives evaluated during the validation process and reinforces the comprehensiveness of the results.

80% of the health professionals were post-graduated, 48% had more than ten years of experience, 72% worked in institutions of the Southeast region, 10.5% of the Midwest and 10.5% of the South regions.

“The ABC of Cancer Guide” was validated by health professionals with final score of 98%. All the participants

Chart 1. Questions of the questionnaire of evaluation of the educational book "The ABC of Cancer Guide" according to the target-public. São Paulo, SP, Brazil, 2024

Questionnaire for children and adolescents		Questionnaire for adults
<b>Variable of Validation: Content</b>		
Purpose	Does "The ABC of Cancer Guide" help you to understand cancer, treatment, procedures and words of the oncologic world?	Does "The ABC of Cancer Guide" demystify cancer in a simple and accessible way?
Organization	Is "The ABC of Cancer Guide" organized and easy to find what you are looking for?	Is "The ABC of Cancer Guide" organized, making it easy to find the information?
Reliability	Is "The ABC of Cancer Guide" reliable and do you believe in its content?	Are the information presented by "The ABC of Cancer Guide" reliable and true?
<b>Variable of Validation: Language</b>		
Clarity	Are the texts of "The ABC of Cancer Guide" easy to read and understand?	Are the texts of "The ABC of Cancer Guide" clear and easy to be read and understood?
Style of the text	Is "The ABC of Cancer Guide" funny?	Has the texts of "The ABC of Cancer Guide" been drafted in a coherent, simple and objective style?
Vocabulary	Were the texts of "The ABC of Cancer Guide" explained in words you were able to understand?	Were the words utilized in "The ABC of Cancer Guide" easy to understand?
<b>Variable of Validation: Presentation</b>		
Layout	The drawings and text of "The ABC of Cancer Guide" facilitate the understanding?	The presentation of "The ABC of Cancer Guide" with drawings and texts facilitates learning?
Images	Are the images of "The ABC of Cancer Guide" explanatory and help to understand the text?	Are the images of "The ABC of Cancer Guide" explanatory and complement the texts?
Typography	Has the color, size and form of the letters utilized in "The ABC of Cancer Guide" made reading easy and fun?	Has the color, size and form of "The ABC of Cancer Guide" facilitated reading?
<b>Variable of Validation: User experience</b>		
Attractiveness	Did you want to open and read "The ABC of Cancer Guide" because you thought it was fun?	Is "The ABC of Cancer Guide" attractive to make you want to read it?
Interaction	Is "The ABC of Cancer Guide" interesting and you want to use it more?	Is "The ABC of Cancer Guide" interesting and stimulates the interaction with the material?
Involvement	Does "The ABC of Cancer Guide" help you to understand and contribute to the treatment?	Does "The ABC of Cancer Guide" promote learning and facilitate the collaboration with the treatment?
Usability	Is "The ABC of Cancer Guide" easy to use?	Is the format of "The ABC of Cancer Guide" easy-to-use?

concurred with the suitability, two participants partially disagreed with the purpose and all of them concurred with the organization and reliability of the material.

One participant partially agreed with the language, one, partially agreed with the clarity and one partially

agreed with the vocabulary. All the participants concurred with the layout, three partially agreed with the images and one partially agreed with typography. The professionals who partially agreed with the indicators presented suggestions for improvement (Chart 3).





Table 1. Sociodemographic and clinical characteristics of children and adolescents. São Paulo, SP, Brazil, 2020

Children and adolescents	
Clinical and sociodemographic variables	n (%)
<b>Sex</b>	
Female	9 (75.0%)
Male	3 (25.0%)
<b>Age range (years)</b>	
05 – 11	4 (33.3%)
12 – 23	8 (66.6%)
<b>Birth region</b>	
Northeast	4 (33.3%)
Southeast	6 (50.0%)
South	2 (16.6%)
<b>Education</b>	
Elementary school I	2 (16.6%)
Elementary school II	4 (33.3%)
High school	6 (50.0%)
<b>Type of cancer</b>	
Leukemia	4 (33.3%)
Lymphoma	4 (33.3%)
Neuroblastoma	3 (25.0%)
Central Nervous System	1 (8.3%)
<b>Phase of the treatment when the guide was received</b>	
Treatment	4 (33.3%)
Follow-up	4 (33.3%)
Recently diagnosed	2 (16.6%)
Maintenance	1 (8.3%)
Palliative care	1 (8.3%)
<b>Treatments performed</b>	
1	10 (83.3%)
> 1	1 (16.6%)
<b>Duration of the last treatment (years)</b>	
0 - 2	7 (58.3%)
> 2	5 (41.6%)

DISCUSSION

The validation of “The ABC of Cancer Guide” from the perspective of children and adolescents, families and health professionals reached a final score of 99.3%, significantly higher than 40% required for adequate materials and 60%

Table 2. Distribution of families and companions according to sociodemographic variables. São Paulo, SP, Brazil, 2024

Adults – relatives and companions	
Sociodemographic variables	n (%)
<b>Sex</b>	
Female	19 (95.0%)
Male	1 (5.0%)
<b>Age range (years)</b>	
18 – 30	3 (15.0%)
31 – 45	12 (60.0%)
46 – 60	4 (20.0%)
> 60	1 (5.0%)
<b>Region of birth</b>	
Northeast	3 (15.0%)
Midwest	1 (5.0%)
Southeast	15 (75.0%)
South	1 (5.0%)
<b>Education</b>	
High school	11 (55.0%)
Graduation	4 (20.0%)
Post-graduation	5 (25.0%)
<b>Kinship with the recipient of the Guide</b>	
Mother	17 (85.0%)
Father	1 (5.0%)
Aunt	1 (5.0%)
Voluntary	1 (5.0%)
<b>Previous knowledge of oncology</b>	
Lay	16 (80.0%)
Previous knowledge	4 (20.0%)

for superior materials according to SAM<sup>14,20</sup>. The result reveals the high quality and acceptance of the book among the participants, demonstrating the validity and suitability as educative material in pediatric oncology.

The inclusion of health multi-professionals reinforced the process of validation ensuring more reliability and comprehensiveness of the results. Previous studies highlight that the interdisciplinary collaboration in creating and validating educative materials is essential to ensure that the content is relevant and adaptable to different demands of the users<sup>21</sup>. This approach allows the incorporation of multiple perspectives, expanding the pertinence and applicability of the educative material in different healthcare setting.

The necessity of educative materials which translate technical-scientific terms into an accessible language is widely acknowledged by the literature. Materials that



Chart 2. Suggestion of relatives and companions to the educative book “The ABC of Cancer Guide”. São Paulo, SP, Brazil, 2024

Suggestions of relatives and companions to “The ABC of Cancer Guide”		
Category	Evaluation	Suggestion
Text style	Disagree	Texts are clear, but I don’t think they are funny
Attractiveness	Partially agree	Actually, no one thinks reading about cancer is fun, but I agree that the explanation is easy to understand
Interaction	Partially agree	It is not the kind of book we need to read several times. Once is enough, and later as a reference
Usability	Partially agree	It is very good

Chart 3. Suggestion of health professionals for the educative book “The ABC of Cancer Guide”. São Paulo, SP, Brazil, 2024

Suggestions of health professionals for the “ABC of Cancer”		
Category	Evaluation	Suggestion
Purpose	Partially agree	Maybe focus more on the treatment and possibility of cure
Purpose	Partially agree	Many patients and their families had doubts about a few words utilized in the explanations. The target-public of our hospital is 100% SUS, most of them are illiterate
Clarity	Partially agree	Same response of the first item. For poorly educated population it is hard to understand
Vocabulary	Partially agree	Again, for poorly educated patients and their families, it is somewhat difficult to understand
Images	Partially agree	Some images could best illustrate the situation described, facilitating children’s understanding
Images	Partially agree	For children, it is satisfactory, but some in-depth information might be necessary for adolescents
Images	Partially agree	Images need to be clearer
Typography	Partially agree	For children, upper case letters would be better

demystify cancer and promote clear understanding of the disease are critical to improve the communication between health teams and families, in addition to helping to reduce the stigma frequently associated with cancer<sup>22</sup>. In line with these findings, “The ABC of Cancer Guide” has been shown to be a suitable resource to facilitate the communication, expand the understanding about the disease and support the adherence to the treatment.

The results show that “The ABC of Cancer Guide” was well received by children and adolescents with a mean final score of 100%. The expanded age range from 5 to 23 years reflects the diversity and highlights the importance of matching the content to different ages. Clarity, lightness and fun aspects of the texts were pointed out by the participants, which is essential to keep the interest and understanding of young readers. Studies indicate that adaptation of the content to the age range and involvement of young adults in the

evaluation of the material are crucial to ensure its efficacy and relevance<sup>23,24</sup>.

The book was awarded a final score of 98.4% by the groups of families and companions, consisting mostly of mothers (85%) with complete high school (55%) and without previous knowledge of oncology (80%). The suggestions received, as making the texts more ludic and improve the attractiveness emphasize the importance of adapting the material to the user’s necessities and perceptions, especially those with poor health literacy<sup>23</sup>. These adjustments are essential to ensure the material is accessible and useful for everyone<sup>23</sup>.

Health professionals, formed mostly by women (90%) with high qualification (80% post-graduated), validated the book with a final score of 98%. The suggestions to include more information about treatment and improve the clarity of the vocabulary are pertinent and reflect the necessity of ensuring the material is understandable for all educational levels and former experiences<sup>24</sup>.



As suggested, images and typography were revised to improve the presentation and usability, especially for individuals with different levels of health literacy and age-range<sup>24-26</sup>.

The international literature highlights the essential role of educative materials to communicate and understand childhood cancer. The Children's Oncology Group Family Handbook: New Diagnosis Guide<sup>27</sup> exemplifies how clear and accessible resources can support children with cancer and their families, promoting adherence to the treatment and reducing anxiety. In line with the findings of the present study, the guide reinforces that structured educative initiatives are essential tools to improve the experience of the patient, strengthening the communication among families and health professionals and favoring humanized and participative care.

Recent studies pointed out the efficacy of educative materials in oncology to improve the understanding and reduce the anxiety of patients and families. A systematic review showed that the use of resources as written materials, audio and interactive contents can facilitate the communication and improve the adherence to the treatment<sup>28</sup>.

In addition, ensure continuous and adaptable education was deemed essential to empower the families and support informed decision-making<sup>28</sup>, which reinforce the present results, suggesting that "The ABC of Cancer Guide" may not only improve the understanding of the disease and treatment, but also, to promote a more patient-centered care<sup>29,30</sup>.

The validation of "The ABC of Cancer Guide" is a significant advance in creating educative materials for childhood cancer. The material validated can facilitate the understanding of childhood cancer and improve the communication among families, children and health professionals. The holistic and interdisciplinary approach utilized strengthens its relevance and suitability as health educative resource.

The validation suggests it can be a useful tool for health education and its use can be expanded to different contexts as hospitals, clinics, wards and home care as an educative tool to improve health literacy and communication among patients, families and health professionals. In addition, the guide can serve as a model to develop policies for health education, reinforcing the necessity of this type of scientifically-proven, culturally-sensitive, adaptable resource for different populations.

Future studies should explore the impact of "The ABC of Cancer Guide" in different cultural and socioeconomic contexts and test its efficacy in alternative formats as videos, interactive apps and other digital media. These approaches can widen the scope and

accessibility of information, making the guide an even more suitable tool to support pediatric patients with cancer and their care.

The limitations of the study are the distribution of the guide when the patients were more vulnerable, which may have impacted the positive evaluations. Furthermore, the development and validation were conducted virtually during the COVID-19 restrictions period, possibly affecting data collection. Another limitation is that the results obtained can't be extended beyond the group investigated (children, adolescents, young adults, families and health professionals), since the method is not applicable to this evaluation. If the material is planned to be used in contexts not addressed in the present study, a specific investigation is necessary.

## CONCLUSION

It was possible to validate the content of "The ABC Cancer Guide", an educative material developed for children with cancer which offers accessible and relevant information for children, adolescents, families and health professionals. The guide can be utilized by health professionals to favor the communication with this public, it has the potential to contribute to the understanding about the disease and its treatment, promoting better adherence to healthcare and support for informed decision-making.

The guide is a valuable tool for health literacy, translating complex technical terms into an understandable language, essential to reduce the anxiety associated with oncologic treatment and empower patients and families. Future studies should explore the use in different cultural and socioeconomic contexts and investigate its applicability in other formats as videos, interactive apps and other digital medias to expand its scope and accessibility.

## CONTRIBUTIONS

All the authors contributed substantially to the study design, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version for publication.

## DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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