VALIDATION OF AN EDUCATIONAL LEAFLET AIMED AT CAREGIVERS OF CHILDREN WITH HEART DISEASE

Validação de folheto educativo voltado a cuidadores de crianças cardiopatas

Validación de un folleto educativo dirigido a cuidadores de niños con cardiopatías

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ABSTRACT

Background: congenital Heart Diseases are structural or functional malformations of the heart that occur during embryonic life, affecting approximately one in every 100 live births worldwide. This study is justified by the need to train caregivers of children with heart disease, enabling them to become key actors in the recovery process, with support from the health care team. **Objective:** to assess the evidence of validity of an educational leaflet on home care for parents and caregivers of children with congenital heart disease. **Methodology:** this is a methodological study focused on the development of an educational technology, conducted in five stages: integrative literature review (16 publications), focus group with parents, interviews with professionals, development, and validation of the leaflet. **Results:** a Likert scale, Content Validity Index, and Content Agreement Index were used, adopting 80% as the minimum validation criterion. The topics of the leaflet included post-discharge care, family adaptation, social impact, and quality of life. **Conclusion:** the 34-page educational leaflet achieved a content validity index of 0.93, a content agreement index of 0.95, and an appearance score of 0.94, being considered appropriate, didactic, and effective for communication between families and professionals.

Keywords: educational technology; caregivers; child care; heart diseases

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RESUMO

Enquadramento: as Cardiopatias Congênitas são malformações estruturais ou funcionais do coração que ocorrem ainda na vida embrionária, afetando cerca de um a cada 100 nascidos vivos no mundo. Este estudo justifica-se pela necessidade de capacitar os cuidadores de crianças cardiopatas, tornando-os protagonistas na recuperação, com apoio da equipe de saúde. **Objetivo:** verificar as evidências de validade de um folheto educativo sobre cuidados domiciliares para pais e cuidadores de crianças cardiopatas. **Metodologia:** trata-se de um estudo metodológico de desenvolvimento de uma tecnologia educativa, que se deu em cinco etapas: revisão integrativa da literatura (16 publicações), grupo focal com pais, entrevistas com profissionais, elaboração e validação do folheto. **Resultados:** utilizou-se Escala de *Likert*, Índice de Validade de Conteúdo e Índice de Concordância de Conteúdo, com 80% como critério mínimo de validação. Os temas do folheto incluíram cuidados pós-alta, adaptação familiar, impacto social e qualidade de vida. **Conclusão:** O folheto educativo, com 34 páginas, obteve validade de conteúdo de 0,93, ICC de 0,95 e escore de aparência de 0,94, sendo considerada adequada, didática e eficaz para comunicação entre famílias e profissionais.

Palavras-chave: tecnologia educacional; cuidadores; cuidado da criança; cardiopatias

RESUMEN

Marco contextual: las Cardiopatías Congénitas son malformaciones estructurales o funcionales del corazón que ocurren durante la vida embrionaria, afectando a aproximadamente uno de cada 100 nacidos vivos en el mundo. Este estudio se justifica por la necesidad de capacitar a los cuidadores de niños con cardiopatías, convirtiéndolos en protagonistas del proceso de recuperación, con el apoyo del equipo de salud. **Objetivo:** verificar la evidencia de validez de un folleto educativo sobre cuidados domiciliarios para padres y cuidadores de niños con cardiopatías congénitas. **Metodología:** se trata de un estudio metodológico orientado al desarrollo de una tecnología educativa, realizado en cinco etapas: revisión integrativa de la literatura (16 publicaciones), grupo focal con padres, entrevistas con profesionales, elaboración y validación del folleto. **Resultados:** se utilizaron una escala Likert, el Índice de Validez de Contenido y el Índice de Concordancia de Contenido, con un 80% como criterio mínimo de validación. Los temas del folleto incluyeron cuidados posalta, adaptación familiar, impacto social y calidad de vida. **Conclusión:** el folleto educativo, con 34 páginas, obtuvo un índice de validez de contenido de 0.93, un índice de concordancia de 0.95 y una puntuación de apariencia de 0.94, siendo considerado adecuado, didáctico y eficaz para la comunicación entre familias y profesionales.

Palabras clave: tecnología educativa; cuidadores; cuidado del niño; cardiopatía

INTRODUCTION

Congenital Heart Diseases (CHDs) are structural or functional abnormalities of the heart that develop during embryonic life. It is estimated that one in every 100 children is born with some type of CHD, representing approximately 130 million cases worldwide (Sociedade Brasileira de Cardiologia, 2020). In the United States, the number of individuals living with congenital heart disease is estimated to be at least 1.4 million, with slightly more than one in every five people affected by the condition (Wu et al., 2018). In the Latin American context, CHDs have a prevalence ranging from 8 to 13 cases per 1,000 live births, being five times more common than other congenital malformations (Gómez-Monroy et al., 2023). In Europe, the prevalence of CHDs varies between 5 and 7 cases per 1,000 live births, according to data from national registries and collaborative studies (Catarino et al., 2017).

In Portugal, congenital heart diseases represent one of the main congenital malformations diagnosed at birth, with an estimated prevalence ranging from 5 to 8.3 per 1,000 births. Among the identified cases, approximately 20% correspond to critical congenital heart diseases, requiring early intervention (Melo et al., 2020).

Severe forms of these malformations account for up to 30% of neonatal deaths and constitute the second leading cause of mortality in children under five years of age (Balasubramanian et al., 2021; Grassi et al., 2022). Furthermore, evidence indicates weaknesses in the early diagnostic process, resulting in undertreatment of approximately 30% of cases and significantly contributing to morbidity and mortality. Factors such as gestational age, maternal age, and birth weight also directly influence the survival of these newborns (Song et al., 2021).

This scenario directly affects family life, requiring complex and continuous care that extends beyond pregnancy, birth, and the postpartum period into childhood. Home care includes continuous medication use, clinical follow-up, possible surgical interventions, and monitoring of the child’s daily habits (Precce et al., 2020). Consequently, the physical and emotional burden experienced by informal caregivers—often family members—who assume full or primary responsibility for care becomes evident (Santos et al., 2020).

In this context, the nursing team, particularly nurses, plays a fundamental role in guiding caregivers and empowering them to provide safe and supported home care. To this end, the development of low-complexity educational technologies, such as leaflets, is necessary to promote health literacy and caregiver autonomy (Martins & Santos, 2020; Oliveira et al., 2020).

Therefore, this study aims to verify the evidence of validity of an educational leaflet on home care for parents and caregivers of children with congenital heart disease.

BACKGROUND

Congenital heart diseases represent a significant challenge for healthcare systems, not only due to their high incidence but also because of the specialized and continuous care they require. Children with CHDs often need medical interventions, therapeutic support, and constant monitoring, which has a direct impact on their caregivers and on the family structure as a whole

(Balasubramanian et al., 2021; Grassi et al., 2022; Precce et al., 2020).

Informal caregivers—most often mothers or other close family members—assume responsibility for direct care tasks, including clinical management, feeding, medication administration, transportation to medical appointments, and monitoring signs and symptoms. Studies indicate that this caregiving burden can negatively affect caregivers' quality of life and emotional well-being (Teixeira et al., 2023).

To minimize risks arising from failures in home care, the importance of health education is emphasized. Health literacy, understood as the ability to comprehend and apply information to make appropriate decisions regarding one's own health and that of those being cared for, is fundamental in this process. Structured educational interventions, such as leaflets and illustrated materials, have demonstrated effectiveness in promoting knowledge acquisition and supported self-care (Andrade et al., 2024; Feitoza, 2015).

Recent studies, such as that by Oliveira et al. (2020), developed an educational leaflet for caregivers of children with special healthcare needs at home and reported excellent acceptance (Content Validity Index = 0.99), highlighting its effectiveness in promoting safe care. Corroborating these findings, Andrade et al. (2024) demonstrated the effectiveness of educational resources such as videos, leaflets, and mobile applications in training caregivers of children, despite the scarcity of studies focused specifically on this population.

Therefore, the need for instruments that support the health literacy of informal caregivers becomes evident, as supported self-care requires family empowerment, with nurses acting as mediators—particularly in cases of chronic childhood conditions such as congenital heart diseases (Fernandes et al., 2017).

METHODOLOGY

This is a methodological study conducted in the Pediatric Department of a tertiary-level hospital in Brazil, which serves as a reference center for the care of children with congenital heart disease in the North and Northeast regions of the country. The study was developed in the following phases: an integrative literature review; a focus group with parents/caregivers; interviews with healthcare professionals from the service to support the development of the educational leaflet; and subsequent validation by technical judges/experts.

Process of technology development

Initially, to gather information for the construction of the technology content, the research question was defined based on health descriptors and inclusion and exclusion criteria. The PICO strategy (acronym for Patient, Intervention, Comparison, and Outcomes) was used to guide this process (Botelho et al., 2011; Ursi, 2006).

Accordingly, the literature search was guided by the following research question: *"What are the main types of care for children with congenital heart disease reported in the literature?"* Searches were conducted in the following databases: LILACS (Latin American and Caribbean Health Sciences Literature), PubMed (developed by the National Center for Biotechnology Information), SciVerse Scopus, and Web of Science. Controlled descriptors were used, such as "congenital heart diseases" or "heart defects," and "nursing care," combined using the Boolean operator AND, with no time restriction.

Subsequently, still in the information-gathering phase, a situational diagnosis was conducted through a focus group, as recommended by Trad (2009). This technique allows the collective construction of narratives based on interaction among participants with shared experiences.

Parents and caregivers receiving care at the hospital where the study was conducted were recruited after signing the Informed Consent Form. According to Trad (2009), the ideal number of participants ranges from six to fifteen; the group comprised nine participants. Chairs were arranged to encourage interaction and visual contact. The duration followed the recommended minimum of 90 minutes, with few guiding topics, prioritizing discussion. The total time varied according to participant availability, the complexity of the topics, and the level of controversy involved.

The number of meetings was determined based on data saturation and the achievement of the intended knowledge, resulting in a single group composed of parents already under follow-up care. Individuals with cognitive impairments or communication difficulties were excluded; however, no participants met these criteria. Sociodemographic data were collected, including place of origin, educational level, marital status, age, sex, occupation, degree of kinship with the child, and duration of follow-up in treatment.

The guiding questions addressed mothers' understanding of the child's condition, including knowledge and diagnostic process, treatment duration, feelings related to the disease, expectations regarding care, and desired information. The study also explored which types of care caregivers intended to assume and which guidelines should be included in a support booklet during hospitalization and after discharge. The number of items was reduced to avoid fatigue and loss of focus.

Subsequently, interviews were conducted with healthcare professionals working in the service, aiming to understand their perspectives on the home care required for these patients and to incorporate their practical experience into the booklet content. Data collection was carried out through semi-structured interviews, in which open-ended questions allowed participants to discuss the proposed topic freely, without predefined answers or conditions (Minayo, 2006). The interviews were audio-recorded and followed a pre-established script, which was made known to participants upon signing the Informed Consent Form.

The sample consisted of professionals working in the hospital's pediatric service, intentionally selected based on their work profile to ensure a qualified, diverse, and multidisciplinary sample. Inclusion criteria were: active involvement in patient care during the study period, a minimum of three years of professional experience—considered sufficient by the researcher to ensure impactful practice with children—and availability and ability to participate.

The recordings were transcribed and analyzed, and recurring and consistent opinions were identified as study results, using the content analysis framework proposed by Bardin (2016). The findings were tabulated, synthesizing verbatim quotations and organizing them into categories. The discourse content was used in alignment with the study objectives, namely the development of an instrument addressing the main difficulties encountered in caring for ill children.

The development of the booklet followed criteria previously validated in the scientific literature (Moreira et al., 2003). The chosen title was *"Living with a Child with Congenital Heart Disease: A Guide for Families,"* addressing care practices that parents should adopt when caring for children with heart conditions.

Regarding language, efforts were made to present information in a logical sequence, using examples and illustrations, emphasizing recommended actions rather than negative statements. Short commands and slightly colloquial language were used, adopting a conversational tone to facilitate understanding; active voice was preferred, with familiar words, simple definitions, and common analogies (Moreira et al., 2003).

Illustrations were carefully selected to support reader understanding and knowledge acquisition (Echer, 2005). Images were created by a designer using Adobe Illustrator CS3 and colored in Adobe Photoshop, opting for a simple and attractive visual style.

After defining the illustrations, layout design, organization, and pagination of the booklet were carried out using Adobe InDesign CS6, with the aim of producing visually appealing material. Arial font, size 14, regular, was used for the main text. For chapter numbering, a more stylized font (MV Boli, size 60) was adopted. Colors were softened to avoid visual clutter and infantilization, highlighting key information in the illustrations. Matte printing was preferred to enhance readability.

Technology validation

Subsequently, the validation process of the developed material was carried out with specialists. To determine the sample size, recommendations from a previously validated model were adopted, which considers a panel of six to twenty judges to be satisfactory (Pasquali, 2009).

Accordingly, a total of thirteen judges were selected using the snowball or network sampling technique (Lobiondo-Wood & Haber, 2001; Polit & Beck, 2019). This stage was conducted through the Lattes Platform, using the search terms "Child Health," "Pediatric Cardiology," and "Health Sciences and Nursing." The curricula were analyzed according to the criteria established by Melo et al. (2024), which consider professional experience, scientific production, and involvement in the study's thematic area.

Once identified, an invitation letter was sent via email explaining the study objectives and inviting participation. After acceptance, participants were provided with the Informed Consent Form to formally confirm their participation, along with a characterization questionnaire, the validation instrument, and a copy of the educational leaflet.

The characterization questionnaire included questions designed to collect sociodemographic and occupational information, such as practice setting (rural or urban), years since graduation, educational level, age, and gender.

In addition, the leaflet validation instrument was based on the Suitability Assessment of Materials (SAM), which enables evaluation of educational materials across the following domains: content; appropriateness of language; graphic illustrations, lists, tables, and charts; layout and typography; learning stimulation and motivation; and cultural appropriateness (Doak et al., 1996).

At this stage, a Likert scale ranging from “strongly disagree” to “strongly agree” was employed, with scores from 1 to 5 assigned to each SAM criterion.

For data analysis aimed at identifying agreement among specialists, the Content Validity Index (CVI) was calculated. A CVI value equal to or greater than 0.78 was considered indicative of validation (Lynn, 1986). The proportion of agreement among judges for each instrument item was measured using a Likert-type scale with scores ranging from 1 to 4, where 1 = Inadequate, 2 = Partially Adequate, 3 = Adequate, and 4 = Totally Adequate (Alexandre & Colucci, 2011).

After evaluating all items individually completed by each judge, the booklet was assessed overall by dividing the sum of all CVI values by the total number of instrument items (Polit & Beck, 2011). Judges’ suggestions were accepted when deemed relevant and organized into a table for subsequent analysis.

This project was submitted to the Research Ethics Committee of a public hospital located in the state of Ceará, Brazil, and was approved under protocol number 1.445.920.

RESULTS

Process of technology development

The initial phase of the technology development process was based on an integrative literature review that analyzed 4,074 articles, of which 16 were selected as the foundation for the development of the booklet. Still within the stage of building the theoretical framework, a situational diagnosis was conducted through a focus group and the collection of opinions from healthcare professionals, followed by the development of the educational material.

Subsequently, the situational diagnosis was carried out through a focus group with nine mothers of children with congenital heart disease, considering the number recommended by Trad (2009) and the data saturation criterion proposed by Bardin (2016). This stage enabled an in-depth understanding of the problem from the perspective of the target population. The sample was heterogeneous in terms of age, educational level, and socioeconomic status, which enriched the collected data. The meeting followed a structured script, ensuring the organization and validity of the information obtained. Among the nine participants, only two were from the state capital. Educational levels ranged from completed higher education to incomplete elementary education; however, all participants were literate. Marital status also varied, with a predominance of stable unions. The group consisted exclusively of women and mothers of the children, with ages ranging from 19 to 47 years.

These stages were fundamental in integrating the researcher with the research problem, providing a solid foundation for the creation and validation of the educational material. Parental participation in the focus group was essential for expressing concerns and doubts, allowing these aspects to be addressed in the educational booklet. One of the main findings was the difficulty experienced by most mothers in explaining their child’s diagnosis, often confusing symptoms with the heart condition itself. Consequently, this topic was extensively discussed and became the first section addressed in the leaflet.

Analysis of the participants’ statements resulted in three thematic categories: the moment of diagnosis, the child in the hospital, and post-discharge care. Parents emphasized their main doubts and the need for more accessible explanations from healthcare professionals, reporting difficulties in understanding medical information and feelings of guilt at the time of diagnosis. In addition, concerns regarding the child's adaptation after discharge were highlighted, including behavior, social interaction, and recognition of warning signs for complications.

Regarding the collection of opinions from professionals, a multiprofessional sample was obtained to explore the topic from different perspectives. Six professionals were selected for interviews: one social worker, one physician, one speech therapist, one occupational therapist, and two nurses. Interviews were conducted in a private setting after participants agreed to take part in the study and were informed about its objectives. All professionals consented to audio recording to streamline the process and enhance interviewer–interviewee interaction. The participants' length of experience in pediatric care ranged from three to 34 years, resulting in a diverse sample with varied professional backgrounds.

The professionals emphasized the importance of parental involvement in care, highlighting that understanding the disease is essential for treatment adherence and complication prevention. Family presence throughout the recovery process—from hospitalization to post-discharge care—was considered fundamental. They also pointed out the need for a didactic approach, using accessible language and focusing on essential information to facilitate parental understanding.

Furthermore, the importance of humanized care and consideration of the family's social conditions were highlighted to avoid barriers to the child's treatment. Accordingly, the booklet should provide clear and objective information, ensuring that parents feel like active participants in their children's care and recovery.

In addition, professionals identified demonstration as an effective strategy for training parents in the care of children with congenital heart disease, allowing them to observe and practice essential actions. Other educational tools were mentioned, such as leaflets, support groups, and multiprofessional care, to facilitate understanding of the clinical condition. Key care aspects to be reinforced included diagnosis, medication, nutrition, hygiene, recognition of warning signs, and children's rights.

Based on the information collected, the main points incorporated into the educational leaflet were: clarification of congenital heart disease and its etiology; accessible language; humanized care; post-surgical care; physical activity; and recognition of signs of complications.

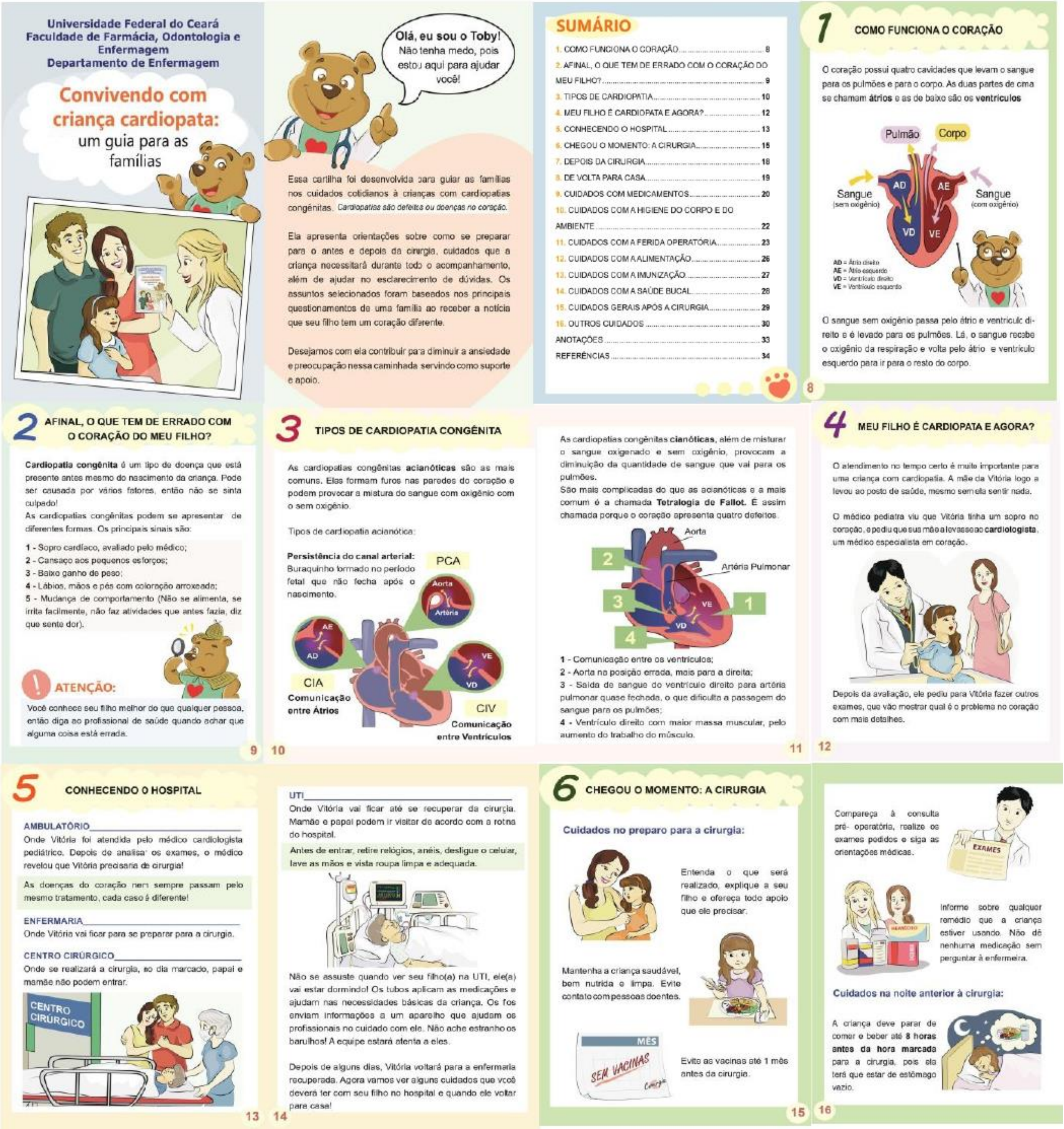
Therefore, the development process involved the selection and organization of content, prioritizing clarity and objectivity. The text adopted a conversational tone, active voice, and short sentences, avoiding negative language. Graphic resources such as bold text, colored boxes, and a mascot were used to highlight essential information. The final booklet consisted of 34 pages, including a table of contents, references, and space for notes, and was printed on matte paper to improve readability. Divided into sixteen sections, the technology explains in an accessible manner the functioning of the heart, types of congenital heart disease, and warning signs. It also provides guidance on medical care, the hospital environment, and preparation for surgery.

Postoperative care is detailed, from hospital recovery to home adaptation.

Additionally, the sections include information on medication use, personal and environmental hygiene, care of the surgical wound, and child nutrition. The material is illustrated to facilitate understanding and reinforces the importance of continuous medical follow-up. The leaflet also addresses essential post-surgical care, including immunization, oral health, and general guidance for the child's daily life. It further discusses social reintegration, such as returning to physical activities and school, emphasizes the importance of ongoing medical follow-up, and concludes with a space for notes and references used in content development.

Moreover, the illustrations were created with the support of a graphic designer, featuring a main character—the bear Toby—who guides the narrative. The family portrayed reflects a culturally common family structure, designed to facilitate reader identification. Visual content was adapted to make information more accessible, using detailed and easy-to-understand images. Layout design was carried out using Adobe InDesign, organizing numbered and highlighted sections to improve readability. The colorful design, in pastel tones, ensures visual appeal without excessive visual clutter, while matte paper enhances legibility.

Finally, the booklet cover was designed to capture the attention of families of children with congenital heart disease, depicting a healthcare professional handing the material to a family. The mascot Toby was included to foster a sense of trust with readers. The chosen title was "Living with a Child with Congenital Heart Disease: A Guide for Families," and the back cover contains information about the authors, location, and year of development. The material also includes a table of contents, introduction, references, and space for caregivers' notes, as presented in Figure 1.



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Convivendo com criança cardiopata:
um guia para as famílias

Essa cartilha foi desenvolvida para guiar as famílias nos cuidados cotidianos à crianças com cardiopatias congênitas. Cardiopatias são defeitos ou doenças no coração.

Ela apresenta orientações sobre como se preparar para o antes e depois da cirurgia, cuidados que a criança necessitará durante todo o acompanhamento, além de ajudar no esclarecimento de dúvidas. Os assuntos selecionados foram baseados nos principais questionamentos de uma família ao receber a notícia que seu filho tem um coração diferente.

Desejamos com ela contribuir para diminuir a ansiedade e preocupação nessa caminhada servindo como suporte e apoio.

SUMÁRIO

1 COMO FUNCIONA O CORAÇÃO

O coração possui quatro cavidades que levam o sangue para os pulmões e para o corpo. As duas partes de cima se chamam **átrios** e as de baixo são os **ventrículos**

AD = Átrio direito
AE = Átrio esquerdo
VD = Ventrículo direito
VE = Ventrículo esquerdo

O sangue sem oxigênio passa pelo átrio e ventrículo direito e é levado para os pulmões. Lá, o sangue recebe o oxigênio da respiração e volta pelo átrio e ventrículo esquerdo para ir para o resto do corpo.

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2 AFINAL, O QUE TEM DE ERRADO COM O CORAÇÃO DO MEU FILHO?

Cardiopatia congênita é um tipo de doença que está presente antes mesmo do nascimento da criança. Pode ser causada por vários fatores, então não se sinta culpado!
As cardiopatias congênitas podem se apresentar de diferentes formas. Os principais sinais são:

1 - Sopro cardíaco, avaliado pelo médico;
2 - Cansaço aos pequenos esforços;
3 - Baixo ganho de peso;
4 - Lábios, mãos e pés com coloração arroxeada;
5 - Mudança de comportamento (Não se alimenta, se irrita facilmente, não faz atividades que antes fazia, diz que sente dor).

ATENÇÃO:

Você conhece seu filho melhor do que qualquer pessoa, então diga ao profissional de saúde quando achar que alguma coisa está errada.

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3 TIPOS DE CARDIOPATIA CONGÊNITA

As cardiopatias congênitas **acianóticas** são as mais comuns. Elas formam furos nas paredes do coração e podem provocar a mistura do sangue com oxigênio com o sem oxigênio.

Tipos de cardiopatia acianótica:

Persistência do canal arterial: Buraquinho formado no período fetal que não fecha após o nascimento.

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As cardiopatias congênitas **cianóticas**, além de misturar o sangue oxigenado e sem oxigênio, provocam a diminuição da quantidade de sangue que vai para os pulmões.
São mais complicadas do que as acianóticas e a mais comum é a chamada **Tetralogia de Fallot**. É assim chamada porque o coração apresenta quatro defeitos.

1 - Comunicação entre os ventrículos;
2 - Aorta na posição errada, mais para a direita;
3 - Saída de sangue do ventrículo direito para artéria pulmonar quase fechada, o que dificulta a passagem do sangue para os pulmões;
4 - Ventrículo direito com maior massa muscular, pelo aumento do trabalho do músculo.

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4 MEU FILHO É CARDIOPATA E AGORA?

O atendimento no tempo certo é muito importante para uma criança com cardiopatia. A mãe da Vitória logo a levou ao posto de saúde, mesmo sem ela sentir nada.

O médico pediatra viu que Vitória tinha um sopro no coração, e pediu que sua mãe a levasse ao **cardiologista**, um médico especialista em coração.

Depois da avaliação, ele pediu para Vitória fazer outros exames, que vão mostrar qual é o problema no coração com mais detalhes.

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5 CONHECENDO O HOSPITAL

AMBULATÓRIO
Onde Vitória foi atendida pelo médico cardiologista pediátrico. Depois de analisar os exames, o médico revelou que Vitória precisaria de cirurgia!

As doenças do coração nem sempre passam pelo mesmo tratamento, cada caso é diferente!

ENFERMARIA
Onde Vitória vai ficar para se preparar para a cirurgia.

CENTRO CIRÚRGICO
Onde se realizará a cirurgia, no dia marcado, papai e mamãe não podem entrar.

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UTI
Onde Vitória vai ficar até se recuperar da cirurgia. Mamãe e papai podem ir visitar de acordo com a rotina do hospital.

Antes de entrar, retire relógios, anéis, desligue o celular, lave as mãos e vista roupa limpa e adequada.

Não se assuste quando ver seu filho(a) na UTI, ele(a) vai estar dormindo! Os tubos aplicam as medicações e ajudam nas necessidades básicas da criança. Os fios enviam informações a um aparelho que ajudam os profissionais no cuidado com ele. Não ache estranho os barulhos! A equipe estará atenta a eles.

Depois de alguns dias, Vitória voltará para a enfermaria recuperada. Agora vamos ver alguns cuidados que você deverá ter com seu filho no hospital e quando ele voltar para casa!

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6 CHEGOU O MOMENTO: A CIRURGIA

Cuidados no preparo para a cirurgia:

Entenda o que será realizado, explique a seu filho e ofereça todo apoio que ele precisar.

Mantenha a criança saudável, bem nutrida e limpa. Evite contato com pessoas doentes.

Evite as vacinas até 1 mês antes da cirurgia.

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Compareça à consulta pré- operatória, realize os exames pedidos e siga as orientações médicas.

Informe sobre qualquer remédio que a criança estiver usando. Não dê nenhuma medicação sem perguntar à enfermeira.

Cuidados na noite anterior à cirurgia:

A criança deve parar de comer e beber até **8 horas antes da hora marcada** para a cirurgia, pois ela terá que estar de estômago vazio.

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Figure 1

Illustrations from the educational leaflet *"Living with a child with congenital heart disease: a guide for families"*

Technology validation

After the development of the educational material, the need arose to validate it with healthcare professionals in order to incorporate both scientific and practical perspectives on the disease and its treatment. Accordingly, thirteen professionals participated as judges: five content experts in pediatric cardiology, four content experts in technology development and instrument validation, and four technical experts. All judges were female. No clear predominance was observed regarding age, with the three age groups showing similar proportions (38.5%, 38.5%, and 23%), with a slightly smaller proportion of professionals over 40 years of age. Regarding academic qualifications, most participants held a master's degree (53.8%), followed by doctoral degrees (38.5%), with a smaller proportion of specialists (7.7%). The predominance of higher academic degrees contributed to a more robust evaluation, suggesting greater professional experience and familiarity with the study theme.

The areas of professional practice among the experts were characterized as follows: 30.8% worked in teaching, research, and clinical practice; 23% exclusively in teaching; 15.3% in both clinical practice and teaching; 15.3% in clinical practice and research; 7.7% exclusively in clinical practice; and 7.7% exclusively in research. Regarding experience with congenital heart disease, 38.5% had six to ten years of experience, 23% had more than ten years, and 15.4% had one to five years of experience. A total of 23% had no direct experience with the topic, which is explained by the inclusion of technical judges selected based on their expertise in the development and validation of technologies, whether or not related to the specific theme.

Therefore, the validation process involved specialists with diverse academic backgrounds and professional experiences, ensuring a rigorous evaluation. Most judges were involved in teaching, research, and clinical practice, with varying levels of experience in congenital heart disease and in the development of educational materials. The mean Content Validity Index (CVI) of the booklet was 0.93, indicating a high level of agreement among specialists, as shown in Table 1.

However, within the Objectives category, item 3 obtained a final CVI of 0.77, which required modifications to the material. This item assessed whether the material was suitable for circulation within the scientific field of pediatric cardiology and was considered partially adequate by two specialists. After revisions and adjustments based on the experts' recommendations, the item was reconsidered. In the Structure and Presentation and Relevance categories, all items were satisfactorily evaluated, and no changes were necessary to achieve the intended objectives.

Table 1

Distribution of specialists' evaluations and Content Validity Index (CVI) per item – Content Judges

Instrument Items	Inadequate	Partially Adequate	Adequate	Totally Adequate	Not Applicable	CVI
1. OBJECTIVES						
1.1 Are consistent with the needs of parents and caregivers to enable them to provide care for children with congenital heart disease.	-	-	4	5	-	1
1.2 Promote changes in behavior and attitudes.	-	1	4	4	-	0,88
1.3 Can be disseminated within the scientific field of pediatric cardiology.	-	2	3	4	-	0,77
2. STRUCTURE AND PRESENTATION						
2.1 The educational material is appropriate for guiding parents and caregivers of children with congenital heart disease.	-	-	2	7	-	1

2.2 The messages are presented clearly and objectively.	-	1	3	5	-	0,88
2.3 The information presented is scientifically accurate.	-	-	2	7	-	1
2.4 The content follows a logical sequence.	-	1	3	5	-	0,88
2.5 The material is appropriate to the sociocultural level of the target audience.	-	1	4	4	-	0,88
2.6 The information is well structured, with appropriate coherence and spelling.	-	1	3	5	-	0,88
2.7 The writing style corresponds to the knowledge level of the target audience.	-	1	5	3	-	0,88
2.8 Information on the cover, back cover, acknowledgements, and/or presentation is coherent.	-	1	1	7	-	0,88
2.9 The illustrations are expressive and sufficient.	-	-	1	8	-	1
2.10 The number of pages is appropriate.	-	-	1	7	-	1
2.11 The size of the title and section headings is appropriate.	-	-	1	8	-	1
3. RELEVANCE						
3.1 topics address the key aspects that should be reinforced.	-	-	2	7	-	1
3.2 The material encourages the reader to acquire knowledge regarding the care of children with congenital heart disease.	-	-	1	8	-	1
3.3 The material addresses the necessary topics for the care of children with congenital heart disease.	-	1	2	6	-	0,88

Therefore, only minor adjustments were required, such as adapting the language to make it more accessible. In addition, the Intraclass Correlation Coefficient (ICC) showed minimal variation among experts' opinions, confirming the cohesion and reliability of the validation instrument. Consequently, the material was considered validated both technically and in terms of appearance.

Furthermore, the main disagreement among the specialists concerned the language used in the material, which was revised to better suit the target audience through structural changes and the addition of explanations for unfamiliar terms.

Content judges suggested changes to the title, the inclusion of additional details about the intensive care unit (ICU), clarification of the roles of other professionals, and clearer information regarding the hospital and its procedures. Technical judges recommended reorganizing the content to follow a chronological sequence, which was promptly implemented. Other modifications included revisions to avoid repetition, corrections of negative phrasing, greater specificity regarding diseases, and clearer identification of the professionals involved. Some illustrations were also redesigned to better emphasize key information. Therefore, the material was validated and considered easy to understand and appropriate for the target audience. The validation process was successful, and the final content met the proposed objectives.

DISCUSSION

Educational materials are essential tools in the processes of learning and healthcare delivery, acting as instruments for knowledge dissemination and community empowerment when developed with quality (Leite et al., 2018). To fulfill this role, such materials must present clear, accurate information aligned with pedagogical objectives, in addition to being attractive, accessible, and consistent with the reality of the target audience, thereby fostering reflection and equipping users for self-care (Rodrigues et al., 2020). This requirement becomes even more relevant given that caregivers frequently experience fear and insecurity in the face of the complexity of care and lack of technical preparation—situations that may be exacerbated by insufficient access to qualified professional guidance (Duarte & Mandetta, 2022).

In this context, validated educational technologies constitute important health education instruments, capable of enhancing individuals' autonomy and strengthening a continuous process of learning and individual and collective transformation. Education delivered through these tools enables a critical understanding of reality, strengthens caregivers' capacity for intervention, and contributes to behavioral changes that positively impact care practices and the environments in which caregivers and children are embedded (Duarte & Mandetta, 2022).

In the present study, content validation was performed using the Content Validity Index (CVI), adopting a minimum agreement cutoff of 0.78, in accordance with recommendations based on the number of judges (Lynn, 1986). Only one item scored below this threshold, which led to adjustments in the language and structure of the material to ensure greater clarity and appropriateness for the target audience without compromising scientific rigor. Judges' suggestions were fully incorporated, including revision of terms, reorganization of information, simplification of illustrations, and removal of content that hindered understanding. After these revisions, the material underwent review by a Portuguese language specialist to ensure greater linguistic accuracy. The overall CVI achieved was 0.93, meeting the minimum value recommended for satisfactory validation of educational instruments (Polit & Beck, 2011).

To assess agreement among evaluators, the Intraclass Correlation Coefficient (ICC) was calculated, a measure that allows evaluation of the degree of consensus among judges. Considering the diversity of possible methods, the study adopted procedures described in the literature and obtained three coefficients indicating total agreement, thereby reinforcing the reliability of the results (Polit & Beck, 2011). The overall assessment indicated that the booklet is suitable as an educational instrument for parents of children with congenital heart disease, standing out for its didactic and instructional nature and for functioning as a facilitating link between families and healthcare professionals.

The findings are consistent with the literature that recognizes nurses as central agents in health promotion and in fostering positive behavioral changes. By prioritizing educational actions and using materials that enhance understanding, nurses contribute to strengthening caregivers' knowledge, preventing avoidable complications, and improving the quality of life of children with congenital heart disease (Duarte & Mandetta, 2022; Rodrigues et al., 2020). The printed educational technology developed in this study, being accessible and tailored to the needs of this population, is reinforced as an effective health education tool.

Despite the promising results, it is important to acknowledge the methodological limitations of the study. The relatively small number of judges may have influenced agreement indices, as larger samples tend to present greater critical variability. In addition, validation focused on content and appearance, without including testing phases with the target audience, such as assessments of readability, usability, or impact on educational practice—elements that could further strengthen the robustness of the findings. Another aspect to consider is the specific sociocultural context in which the booklet will be applied, which may limit generalizability to other populations.

Recognizing these limitations does not diminish the relevance of the research; rather, it guides future improvements. Therefore, further validation stages involving caregivers and children with congenital heart disease are recommended, along with an expanded number of evaluators and practical applicability testing in different Primary Health Care settings.

CONCLUSION

The booklet entitled "Living with a Child with Congenital Heart Disease: A Guide for Families" demonstrated evidence of validity based on rigorous and reliable criteria established in the literature. The development process made it possible to identify concrete findings, such as recurring doubts among families, gaps in knowledge regarding warning signs, and difficulties in daily management, which guided the creation of a clear, accessible material aligned with users' needs.

The developed booklet underwent a continuous evaluation process, with knowledge being adapted and refined at all stages of its construction. This process resulted in a valid instrument intended to standardize care and address knowledge gaps among the target audience, within a cyclical process of education and knowledge acquisition. Nevertheless, caution is warranted to avoid overgeneralization, as the direct impact of the booklet on clinical outcomes or objective behavioral changes among families was not measured. Therefore, the material should be understood as a promising educational tool rather than a determinant of clinical effectiveness.

As a practical recommendation, the incorporation of the booklet into nursing consultations is encouraged, using it as a supporting resource for continuing education and facilitating the provision of valid, accessible information to families.

Finally, future studies are recommended to include usability assessments in different contexts, longitudinal studies on knowledge retention over time, and effectiveness studies measuring gains in knowledge, self-confidence, caregiving practices, and potential effects on treatment adherence and prevention of complications.

CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest.

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