ORIGINAL ARTICLE

Building knowledge and welcoming children with myelomeningocele and their families: development and validation of an educational booklet

Construindo saberes e acolhendo a criança com mielomeningocele e sua família: elaboração e validação de uma cartilha educacional

Crear conocimiento y acoger a los niños con mielomeningocele y a sus familias: desarrollo y validación de un folleto educativo

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Resumo

Objetivo: Construir e validar uma cartilha educacional sobre mielomeningocele e realizar a validação de conteúdo e análise semântica.
Métodos: Estudo metodológico realizado em três etapas: 1) revisão da literatura, realizada nas bases de dados National Library of Medicine (PubMed) e Biblioteca Virtual em Saúde (BVS), utilizando os descritores “mielomeningocele”, “genética” e “fatores ambientais”; 2) elaboração da cartilha, com base em conhecimento teórico; 3) validação de conteúdo e análise semântica.
Resultados: Da revisão narrativa da literatura foram identificados 14 artigos que após leitura foram agrupados em três categorias temáticas: definição, etiologia e tratamento. Para a construção da tecnologia educacional, utilizou-se uma plataforma de *design* gráfico e produziu-se a cartilha denominada *“Conhecendo a Mielomeningocele”,* com 15 páginas, em linguagem acessível e embasamento científico. A narrativa é conduzida por personagens fictícios, “Milo e seus amigos”, crianças em idade escolar diagnosticadas com mielomeningocele, que explicam a condição de maneira didática e interativa, visando contribuir para a literacia em saúde e a capacitação das famílias no cuidado à criança. As etapas de validação de conteúdo e análise semântica foram conduzidas por um comitê de juízes especialistas e por membros de família de crianças com mielomeningocele, respectivamente. Obteve-se um percentual de concordância igual ou maior a 80.
Conclusão: A tecnologia educacional construída foi validada e está apta a ser aplicada com famílias de crianças diagnosticadas com mielomeningocele.

Keywords
Neural tube defects; Educational Technology; Health education; Pediatric Nursing; Family

Abstract

Objective: To construct and validate an educational booklet on myelomeningocele and to carry out content validation and semantic analysis.
Methods: Methodological study carried out in three stages: 1) a literature review, carried out in the National Library of Medicine (PubMed) and Virtual Health Library (VHL) databases, using the descriptors “myelomeningocele”, “genetics”and “environmental factors”; 2) development of a booklet, based on theoretical knowledge; 3) content validation and semantic analysis.
Results: The narrative literature review identified 14 articles which, after reading, were grouped into three thematic categories: definition, etiology and treatment. A design platform was used to build the educational technology. A 15-page booklet called “Getting to know Myelomeningocele” was produced, with accessible language and a scientific basis. The narrative is led by fictional characters, “Milo and his friends”, schoolchildren diagnosed with myelomeningocele, who explain the condition in a didactic and interactive way, with the aim of contributing to health literacy and training families in caring for children. The content validation and semantic analysis stages were

Descritores
Defeitos do tubo neural; Tecnologia educacional; Educação em saúde; Enfermagem pediátrica; Família

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conducted by a committee of expert judges and family members of children with myelomeningocele, respectively. Three rounds were carried out, obtaining a percentage of agreement equal to or greater than 80.
Conclusion: The educational technology developed has been validated and is suitable for use with families of children diagnosed with myelomeningocele.

Resumen

Objetivo: Elaborar y validar un folleto educativo sobre el mielomeningocele y realizar una validación del contenido y un análisis semántico.
Métodos: Estudio metodológico realizado en tres etapas: 1) revisión bibliográfica, realizada en las bases de datos National Library of Medicine (PubMed) y Virtual Health Library (BVS), utilizando los descriptores «mielomeningocele», «genética» y «factores ambientales» ; 2) elaboración del cuadernillo, a partir de los conocimientos teóricos; 3) validación del contenido y análisis semántico.
Resultados: La revisión narrativa de la literatura identificó 14 artículos que, tras su lectura, se agruparon en tres categorías temáticas: definición, etiología y tratamiento. Se utilizó una plataforma de diseño gráfico para construir la tecnología educativa. Se elaboró un folleto de 15 páginas titulado 'Conociendo el mielomeningocele', con un lenguaje accesible y una base científica. La narración está protagonizada por personajes ficticios, «Milo y sus amigos», escolares diagnosticados de mielomeningocele, que explican la patología de forma didáctica e interactiva, con el objetivo de contribuir a la alfabetización sanitaria y formar a las familias en el cuidado de los niños. Las etapas de validación de contenido y análisis semántico fueron realizadas por un comité de jueces expertos y familiares de niños con mielomeningocele respectivamente. Se realizaron tres rondas, obteniéndose un porcentaje de acuerdo igual o superior al 80.
Conclusión: La tecnología educativa desarrollada ha sido validada y es adecuada para su uso con familias de niños diagnosticados de mielomeningocele.

Descriptores
Defectos del tubo neural; Tecnología educativa; Educación para la salud; Enfermería pediátrica; Familia

Introduction

Myelomeningocele (MMC) is a congenital malformation of the central nervous system, which occurs between the fourth and fifth week of gestation, also known as neural tube closure defect (NTCD) that results in a vertebral opening, forming a cystic protrusion, with exposure of the spinal cord. This alteration can occur in different levels, and the closer the spinal cord lesions are to the cranial segments, the more severe the neurological problems will be. (1,2)

The global incidence of MMC ranges from 0.1 to 10 cases per 1,000 live births, depending on geographical region and ethnicity, and is more prevalent in Caucasians. It is also the second leading cause of neonatal death. In the United States, the incidence is approximately 1 case per 4,000 live births. In Brazil, the incidence varies depending on the region, with an estimated frequency of 1 in every 1,000 to 2,000 live births. (3,6)

Its etiology is multifactorial, and among the risk factors associated with MMC, the following can be mentioned: diabetes mellitus, obesity, epigenetic and genetic factors, the use of anticonvulsant drugs and folic acid deficiency during the early period of neural tube development.(9,10) Studies have shown that the supplementation with folic acid (the synthetic formula of folate - vitamin B9) during pregnancy is related to a 30% reduction in spina bifida rates in the United States, suggesting that folate deficiency is a predisposing factor for NTDs.(7,9) The mechanism by which folic acid supplementation prevents neural tube diseases is still not fully understood. However, it is known that folic acid derivatives are essential for DNA synthesis and methylation, cell division, tissue growth and the formation of red blood cells. (9-11)

Treatment for MMC is surgical, which can be performed either in utero or after birth. When performed prenatally, amniotic fluid is collected for fetal karyotype analysis in order to exclude associated chromosomal disorders.(11,12) However, the neurological problems associated with MMC often lead to comorbidities for the child, such as hydrocephalus, neurogenic bladder, congenital clubfoot, among others, which require specific treatments and additional care that must be provided by a multi-professional team, composed of a pediatrician, neurologist, orthopedist, urologist, nurses, occupational therapy, physiotherapy, etc.(13,14)

Due to its complexity, MMC is a health condition that affects not only the child's biopsychosocial development, but also the dynamics of their family, resulting in limitations, financial difficulties and compromised quality of life. (17,18)

The necessity of clinical follow-up treatment will rely both on the body systems affected by the neural tube defect and the chronicity of the disease. In this context, it is essential to include the family in the treatment process, not only in the hospital context, but also in the transition of care, by developing their competence to provide the necessary care for the child at home. (14)

Therefore, since health education is the main factor in promoting the literacy of these families, the aim of this study was to construct an educational booklet on myelomeningocele and carry out content validation and semantic analysis. [19]

Methods

Methodological study conducted in three stages: 1) narrative literature review; 2) preparation of educational material; 3) content validation and semantic analysis.

In the first phase of the narrative literature review, searches were conducted in both the Virtual Health Library (VHL) and the U.S. National Library of Medicine (PubMed) databases. Using the following descriptors registered in the DeCS (Descriptors in Health Sciences) and the corresponding MeSH (Medical Subject Headings): Myelomeningocele (Mielomeningocele), Genetics (Genética), and Environmental Factors (fatores ambientais), paired together. The Boolean operator "AND" was used. The review was guided by the question: "What genetic and epigenetic factors are associated with the etiology of myelomeningocele?

The inclusion criteria defined were: scientific articles available in Portuguese, English or Spanish; with full text and open access. The time frame stablished was from 2000 to 2022, regarding the recent scientific production about this topic. Editorials, experience reports, theoretical essays, reflection studies, books and other reviews, and gray literature were excluded.

The second phase was the construction of the booklet. Within the various educational technologies available, the booklet format was chosen because of its practicality and potential reach, since the material is expected to be widely distributed in both physical and digital formats, in all the health services that children with MMC and their families attend, facilitating access to families of children with this condition, making the access to information easier.

The free graphic design platform CANVA® was used to develop the booklet. It is an online platform that provides access to templates and illustrations. Illustrations with didactic and interactive features were selected to develop the booklet. The color palette applied was chosen in reference to 'Yellow October', a month dedicated to raising awareness of myelomeningocele.

The third phase involved content validation made by expert judges and semantic analysis with the target population. For content validation, a committee of expert judges was formed which satisfied the following inclusion criteria: be a teacher and/or administrative technician in education and/or a doctoral student at a Higher Education Institution having practical/clinical experience and/or conduct research on the topic addressed and/or work on an extension project. The evaluators were chosen based on their Lattes CVs available on the platform of the National Council for Scientific and Technological Development (CNPq) and their involvement in extension projects at the Federal University of São Paulo (UNIFESP). Examples of these projects include Clube do Saber (https://www.unifesp.br/reitoria/proec/programas-e-projetos) and INFANTE (www.unifesp.br/reitoria/proec/programas-e-projetos), whose main objective is to promote health education.

The selected expert judges were contacted individually by e-mail. The invitations were sent out with the objective of the research. After acceptance, the booklet was send for reading and analysis as well as a copy of the Informed Consent Form (ICF). Face-to-face meetings were scheduled with the researcher (first author) and each specialist individually to discuss and reach consensus on each item of the educational material.

For the evaluation of the material by the committee of judges, three axes were defined: language, illustration and content. The questions were: (1) language "Is the language of the booklet accessible to the lay public?"; (2) Illustration "Are the images easily understood by the target audience?"; (3) content "Is the general content of the material coherent?". The Delphi technique was used to reach the consensus, with a criterion at least 80% of agreement on each axis.

The research was approved by the Research Ethics Committee linked to a Higher Education Institution (Certificate of Presentation for Ethical Appraisal: 77785724.0.0000.5505). This study complied with the ethical standards set out in Resolution 510/2016, which provides regulatory standards for research in the social sciences and humanities. All the families received a copy of the signed Informed Consent Form (ICF) after being informed about the research and agreeing to participate.

Chart 1. Search strategy used in the narrative review

PubMed	"Environmental Factors" AND Myelomeningocele AND Genetics "Environmental Factors" AND Myelomeningocele
BVS	"Environmental Factors" AND Myelomeningocele AND Genetics "Environmental Factors" AND Myelomeningocele

Results

After conducting the narrative review, 103 articles were identified, of which 89 were excluded according to the following criteria: 70 for duplication in the databases; 8 after reading the abstract; and 11 for not answering the review question, resulting in 14 articles included in the review (Figure 1). The articles were grouped into the following themes: articles on the definition of MMC, etiology and treatment.

Subsequently, a version of the booklet called 'The Diagnosis of Myelomeningocele' was created, with 15 pages, in accessible, clear and concise language; in question and answer style, which was submitted to validation phase 3 (Figure 2). The content validation process took place in three rounds, including 7 judges. In the first round, there was 100% agreement on the content of the booklet; 67% agreement on the illustrations and 33% agreement on the language item. Regarding the illustrations, the expert judges pointed out the necessity of including additional anatomical images in order to make it easier for the lay public to understand the pathology. For the language, the expert judges emphasized the demand to make it more accessible to the target audience, in order to ensure a better understanding of the content and, consequently, the effectiveness of the material in health education. In the second round, there was 100% agreement on the illustration and 67% agreement on the language. The expert judges suggested changing the title of the booklet from 'The Diagnosis of Myelomeningocele' to 'Getting to know Myelomeningocele', in order to better reflect the educational objective of the material. In the third round, 100% agreement was obtained on all items.

Moreover, for the semantic analysis, four families of children with MMC treated at a pediatric neurosurgery outpatient clinic, located in a referral service, participated doing the reading and discussion together with the first author, and there was 100% agreement in a single round. The families were unanimous in recognizing the importance of the booklet as an informative

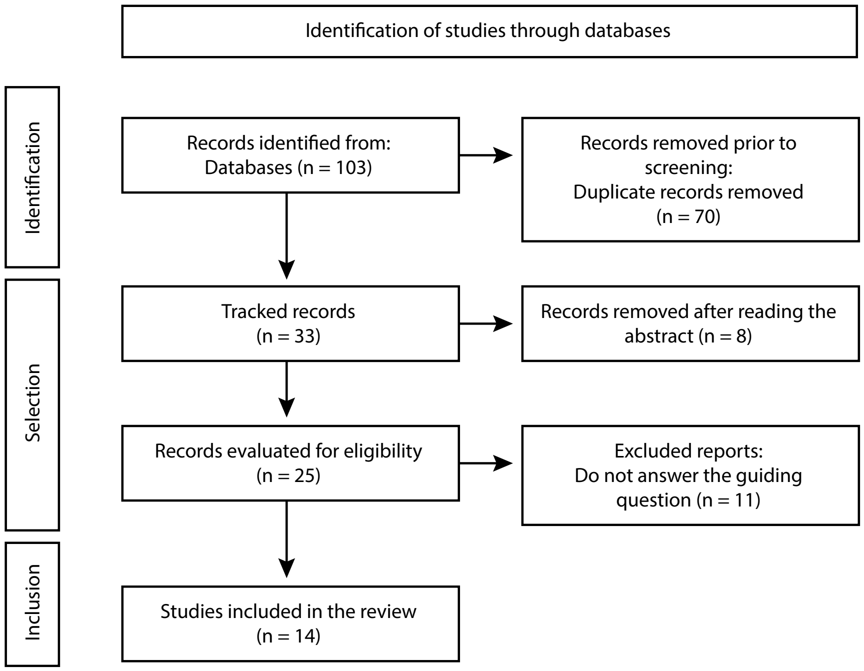

Figure 1. Flowchart showing the search and selection process for the articles included in the narrative review. Created with prisma-statement.org/

material, highlighting the reliability of the information and its relevance for lay people to understand the pathology, especially right after the diagnosis, when most family members and/or guardians appeal to the internet as their main source of information about the condition, without checking the veracity of the information they are consuming.

Thus, the final version of the booklet entitled 'Getting to know Myelomeningocele' was developed, comprising 15 pages in a question-and-answer format (Figure 2).

The booklet explores three central themes: the etiology of MMC, explaining genetic and environmental factors and folic acid deficiency as possible determinants of the condition; treatment, detailing surgical strategies and the interdisciplinary care needed to properly manage the disease; and complementary information, which addresses quality of life, social integration and the use of support technologies, with the aim of enhancing the autonomy and participation of affected children.On the first page of the booklet, readers are introduced to characters who will guide their understanding of the condition, with 'Milo' being responsible for presenting questions that lead to the subsequent topics. The name 'Milo' was chosen as a mnemonic that refers to MMC. On pages 3, 4 and 5, the content covers the definition of myelomeningocele under the heading "What is myelomeningocele?", providing a clear and concise basis. The etiology of the disease is discussed on page 6, under the heading "Why does it happen?", with an emphasis on pathophysiological aspects and possible associated causes. The treatment of myelomeningocele is discussed on pages 7 and 8, under the topic "What is the treatment?", providing a comprehensive overview of the therapeutic options available. On page 9, a section entitled "Where can I find support? ", lists websites, contacts for institutions and government bodies that provide additional support, as well as details on the rights of children and their families.The last page contains a space called "What do I want to write down?", allowing readers to record doubts or relevant information to be discussed with health professionals. The booklet ends with the names of the authors responsible for producing it, as well as the logos of the academic institution.

The booklet will be available to the target public in the second semester of 2025, though the social media accounts of the following extension projects: "Clube do Saber" and "INFANTE", both affiliated with the Federal University of São Paulo (UNIFESP).

Discussion

During pregnancy, parents usually have positive expectations about the baby's health and the course of the pregnancy. However, diagnosis of congenital anomalies, genetic diseases or complications can cause an intense impact on family dynamics. (17,18)

In this context, educational technologies are proving to be effective and accessible tools on the promotion of health literacy and encouraging the active involvement of patients and their families in healthcare. (19)

Among the different types of technology available, the booklet format is a particularly valuable resource when it comes to health education, as it is able to combine clear language, didactic organization and visual appeal, which facilitates understanding by different audiences. (19,20)

In addition, their practicality in terms of reproduction and distribution makes them versatile tools for democratize scientific knowledge in an inclusive way, both digitally and physically. (19,21)

As a result, the booklet "Getting to know Myelomeningocele" was designed to be an educational tool capable of increasing the knowledge of families of children diagnosed with myelomeningocele, aiming to promote health literacy and family empowerment, especially in times of expectation such as the prenatal or postnatal stages. (19)

In addition, educational material can also play a key role in raising awareness among health professionals of the importance of interprofessional collaborative practice. This aims to encourage the development of support and communication networks, especially in primary care. Using the material in different contexts has become an efficient strategy capable of improving the health care situation of the patients, as well as also being a way of offering support to their families.

Thus, after undergoing a content validation process performed by specialists and semantic analysis made by the target audience, the booklet "Getting to know Myelomeningocele" can be used as an auxiliary resource in everyday professional health practice and as support for families. (19-21)

I. Etiologia da Mielomeningocele: Fatores Genéticos, Ambientais e Carência de Ácido Fólico

II. Tratamento da Mielomeningocele: Abordagem Cirúrgica, Reabilitação e Cuidados Multidisciplinares

III. Informações Adicionais: Qualidade de Vida, Inclusão Social e Tecnologias Assistivas

CONHECENDO
A
MIELOMENINGOCELE

Dia Internacional de Conscientização da Mielomeningocele
25 de Outubro

Essa cartilha foi produzida por:

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Oi! Eu sou o Milo e, como seu bebê, eu e meus amigos também fomos diagnosticados com mielomeningocele quando ainda estávamos na barriga das nossas mamães ou assim que nascemos! Eu e meus amigos queremos te contar um pouco mais sobre esse diagnostico! Vamos lá?

- O que é?
- Por Que Acontece?
- Qual o Tratamento?
- Onde Posso Buscar Apoio?
- O Que Quero Anotar?

O que é?

Dentro dessa capa protetora, chamada meninge, encontramos também a medula espinhal que é formada por vários fios (conhecidos como nervos) que percorrem todo nosso corpo e tem como função fazer a comunicação entre o nosso cérebro e o restante do nosso corpo.
Por isso, dependendo do lugar da coluna que essa bolsa está e quantos fios ela puxa, algumas coisas podem acontecer.
Mas fica tranquilo(a), que já vamos te contar mais sobre!

Por que acontece?

Você sabe por quê a mielomeningocele acontece? Não? Pode deixar que eu vou te contar um pouquinho!
A MMC pode acontecer com mais frequência se a mamãe tiver certos problemas de saúde, como:
- Diabetes Mellitus (DM).
- Obesidade.
- Uso de medicamentos antiepiléticos sem recomendação médica
- Deficiência de ácido fólico (vitamina B9)

Onde posso buscar apoio?

Você sabia que existem alguns lugares que você pode te dar mais informações sobre a mielomeningocele? Vou te contar alguns agora mesmo!

Antes de tudo, não esqueça de contar com a equipe de saúde do seu bebê!

Figure 2. Illustrations of the booklet ''Getting to know Myelomeningocele", created using the CANVA® platform.

The present study has the following limitation: the size of the intended audience that participated, in only one scenario of public assistance, with a homogeneous population, which represents a Brazilian municipality. Given the country's cultural diversity, applying the material with families from other Brazilian states is recommended.

Conclusion

The booklet "Getting to know Myelomeningocele" has been validated and is ready to be applied with families of children with myelomeningocele. It is an educational technology with potential to contribute to health literacy and the training of families in child care practices. The dissemination and implementation of the material will begin in digital and printed format, after the semantic analysis has been expanded with the target audience.

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Contributions

Elicar MC, Mandetta MA, Diana P, Santino SF, Balbino FS, Collange NZ, Santos LG and Malinverni ACM declare that they contributed to the study design, data collection, analysis, interpretation and the writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

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