

# Construction and validation of a booklet for home palliative care after hospital discharge

Construção e validação de cartilha para cuidados paliativos domiciliares após alta hospitalar  
Elaboración y validación de cartilla para cuidados paliativos domiciliarios después del alta hospitalaria

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## Abstract

**Objective:** To construct and validate an educational booklet for home palliative care after hospital discharge.

**Methods:** This is a methodological study developed in three stages: bibliographic survey, booklet construction and material validation by palliative care experts and patient caregivers. The validation process was carried out by 8 experts and 12 target audience representatives, selected for convenience. The Minimum Content Validity Index of 0.80 was considered for content validation and minimum agreement of 75% for appearance validation.

**Results:** The booklet “*Eu cuido, nós cuidamos – cuidados domiciliares a pacientes em cuidados paliativos*” consists of 28 pages. In the content validation by experts, the global CVI obtained was 1.0 and the booklet was unanimously approved by the target audience representatives, with agreement index of 1.0.

**Conclusion:** The educational booklet was validated regarding content and appearance, and can be used by caregivers in the performance of home palliative care and by nurses for guidance at hospital discharge.

## Resumo

**Objetivo:** Construir e validar cartilha educativa para cuidados paliativos domiciliares após a alta hospitalar.

**Métodos:** Estudo metodológico desenvolvido em três etapas: levantamento bibliográfico, construção da cartilha educativa e validação do material por especialistas em cuidados paliativos e cuidadores de pacientes. O processo de validação foi realizado por 8 especialistas e 12 representantes do público-alvo, selecionados por conveniência. Considerou-se o Índice de Validade de Conteúdo mínimo de 0,80, para validação de conteúdo e concordância mínima de 75% para validação de aparência.

**Resultados:** A cartilha intitulada “*Eu cuido, nós cuidamos – cuidados domiciliares a pacientes em cuidados paliativos*” é composta por 28 páginas. Na validação de conteúdo pelos especialistas, o IVC global obtido foi 1,0 e a cartilha foi aprovada por unanimidade pelos representantes do público-alvo, com índice de concordância 1,0.

**Conclusão:** A cartilha educativa foi validada quanto ao conteúdo e aparência, podendo ser utilizada por cuidadores na realização de cuidados paliativos domiciliares e por enfermeiros para as orientações na alta hospitalar.

## Resumen

**Objetivo:** Elaborar y validar cartilla educativa para cuidados paliativos domiciliarios después del alta hospitalaria.

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Conflicts of interest: nothing to declare.

**Métodos:** Estudio metodológico desarrollado en tres etapas: recopilación bibliográfica, elaboración de cartilla educativa y validación del material por especialistas en cuidados paliativos y cuidadores de pacientes. El proceso de validación fue realizado por ocho especialistas y 12 representantes del público destinatario, seleccionados por conveniencia. Se consideró el Índice de Validez de Contenido mínimo de 0,80 para la validación de contenido, y concordancia mínima de 75 % para validación de apariencia.

**Resultados:** La cartilla titulada "Yo cuido, nosotros cuidamos: cuidados domiciliarios a pacientes en cuidados paliativos" está compuesta por 28 páginas. En la validación de contenido por los especialistas, el IVC global obtenido fue 1,0 y la cartilla fue aprobada por unanimidad por los representantes del público destinatario, con un índice de concordancia de 1,0.

**Conclusión:** La cartilla educativa fue validada respecto al contenido y apariencia y puede ser utilizada por cuidadores en la realización de cuidados paliativos domiciliarios y por enfermeros para dar instrucciones en el alta hospitalaria.

## Introduction

Palliative care (PC) is active holistic care for individuals of all ages, with serious health-related suffering due to severe illness, especially to those close to the end of life. It aims to improve the quality of life of patients, their families and caregivers.<sup>(1)</sup>

Worldwide, 53 million adults require PC, of which 76% live in low- or middle-income countries, such as Brazil.<sup>(2)</sup> Thus, discussing strategies to offer safe and effective care in the home environment by the caregiver is essential, given the high number of individuals in such a condition.

Generally, after hospital discharge, patients need safe care, in order to eliminate the risks of technical malpractice and, consequently, reduce the number of rehospitalizations and health expenses, in addition to their suffering and that of their family members. Considering that, in most cases, caregivers are a lay family member and without technical knowledge, it is necessary to train and support educational care about the care to be developed at home, especially if a patient makes use of care devices.<sup>(3,4)</sup>

Basic guidance on a patient's condition and needs is essential to make possible continuity of care provided by family caregivers at home and should be performed during hospitalization.<sup>(3)</sup>

Among the various information technologies, guidelines and communication, educational materials, such as brochures and booklets, contribute to the educational process to caregivers and family members, favoring the support of care offered to patients, with the objective of improving their quality of life and also alleviating caregivers' insecurity and uncertainties.<sup>(5)</sup>

Thus, this study aimed to construct and validate an educational booklet for home PC after hospital discharge.

## Methods

This is a methodological study developed in three stages: bibliographic survey, educational material preparation, and material validation by experts in the subject and target audience representatives.

The booklet was constructed according to the recommendations for production and effectiveness of educational materials, according to content, language, illustration, layout, motivation, and culture.<sup>(6)</sup> In the process of constructing the booklet, a bibliographic survey was conducted on home care in Ministry of Health<sup>(7)</sup> manuals and the Brazilian National Academy of Palliative Care (ANCP - *Academia Nacional de Cuidados Paliativos*),<sup>(8)</sup> national and international articles and nursing text book.<sup>(9)</sup>

Data were collected from December 2018 to May 2019, in inpatient units of a university hospital in the countryside of São Paulo. It is a medium-complexity institution with 50 beds and, of these, 10 are exclusive for hospitalization of patients under PC.

In order to include in the booklet relevant themes that are consistent with the needs of its target audience, the prior knowledge and opinion of family members and caregivers of patients under PC about home care were investigated through interviews.

The stage of data collection with caregivers had a consecutive and non-probabilistic sample consisting of 10 caregivers, aged 18 years or older, who were accompanying patients during hospitalization.

The caregivers were invited to participate in the study and informed about the objectives. After acceptance, the caregivers were referred to a private room and an Informed Consent Form (ICF) was

introduced. After agreement and signature of the ICF by the participants, the interviews were initiated using a structured script with questions that addressed: patient capacity to perform self-care; need for assistance for medication administration at home; use of feeding devices; characteristics of eliminations (spontaneous or not) and the need to use diapers or collectors; presence of stomas; degree of patient mobility and need for assistive devices; content suggestions to make up the booklet.

The script was constructed by the main researcher and submitted to three experts for appearance and content validation. The interviews had an average duration of 15 minutes.

After defining the booklet content, a photo session was held at a low-fidelity laboratory of *Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo*, with the participation of three volunteers (two representing caregivers and one representing a patient), with the objective of obtaining illustrative images related to content. Then, design and diagramming were carried out by a professional expert in communication and advertising and the first version of the booklet was created.

To validate the booklet, we used the concept of content validity and appearance, i.e., a judgment that seeks to measure the adequacy of assessment items in relation to content, in addition to agreement among experts.<sup>(10)</sup>

The invitation letter to experts was sent by email, together with the ICF, the first version of the booklet and its protocol of judgment and an instrument for sociodemographic characterization. The experts were given a period of 30 days for material assessment, instrument completion and return to the researcher. It was optional for the experts to add in the protocol suggestions or comments on the material.

We invited 10 professionals with care, teaching or research experience under PC and health education. However, only eight answered, agreeing to participate. The search for experts occurred for convenience, through the indication of PC professionals and the number of experts included in the study was considered adequate.<sup>(11)</sup>

A judgment protocol was adapted to validate content and appearance by experts and the 21 items

were structured into content, language, illustrations, layout, motivation, and culture.<sup>(12)</sup> The experts carried out an analysis corresponding to the relevance of each item, (1 - irrelevant, 2 - little irrelevant, 3 - relevant, 4 - extremely relevant).<sup>(13)</sup> Moreover, the instrument was in room for comments and suggestions. Subsequently, the booklet was submitted to edition for incorporation of experts' recommendations and suggestions, resulting in a second version.

To select the target audience representatives for content and appearance assessment, the following inclusion criteria were adopted: to be literate and not to have visual alterations that would compromise the booklet reading at the time.

Participants were given the second version of the educational booklet and the ICF for signing, in two copies, being informed about the study. To assess the educational booklet by the target audience representatives, an instrument adapted from the Suitability Assessment of Materials (SAM) was applied, a version translated and adapted for Brazilian Portuguese,<sup>(14)</sup> containing 15 items. Each participant was instructed to read the booklet, analyze the text and images, and then fill out the assessment instrument, scoring answers in 0 - not adequate, 1 - partially adequate, 2 - totally adequate. After the sum of all suggested items and calculations, the material was classified as superior, adequate or non-acceptable.

When accepting to participate in the study, the target audience representatives were sent to a private room, where they remained alone to read the booklet for 15 minutes. Afterwards, the researcher remained in the room during the completion of the assessment instrument by each participant, and at that moment, doubts were clarified and the assessment instrument and the ICF signed were collected.

Descriptive analysis of data related to characterization of experts and target audience representatives was performed. To verify content validity, Content Validity Index (CVI) was used: Item-level Content Validity Index (I-CVI) and global CVI were calculated for each item of the instrument. An index equal to or greater than 0.80 was considered desirable in content validation.<sup>(10)</sup>

Statistical analysis of agreement, according to each item, was performed by adjusting the propor-

tions of experts who agreed with the booklet relevance. For this, the Binominal test was used, being pertinent a p value equal to or higher than 0.85. For this analysis, the level of significance adopted was 5%.

The project was approved by the Institutional Review Board (IRB) of *Escola de Enfermagem de Ribeirão Preto*, under Opinion 2,921,604 and according to Resolution 466/2012.<sup>(15)</sup>

## Results

The final version's size is 190x210mm (closed) and has 28 core pages (printed duplex). The themes were grouped by similarity and adapted to popular language. In all, the contents consisted of 15 topics about general care with patients under PC and a topic on caregiver care. The booklet was entitled “*Eu cuido, nós cuidamos – cuidados domiciliares a pacientes em cuidados paliativos*”.

The preparation of the first version started from a bibliographic survey about relevant contents to make up the booklet and suggestions pointed out by caregivers during the interviews. The main questions and suggestions of caregivers are presented in Chart 1.

**Chart 1.** Synthesis of doubts and suggestions of the caregivers interviewed

Number of caregivers	Doubts and suggestions expressed
7	Doubt on nasoenteric tube handling (diet, medication and water administration)
4	Doubts on how to care for stomata (tracheostomy and colostomy)
3	Suggestion: introduce content on how to offer bed bath
2	Doubts on what to do when the nasoenteric probe is displaced
1	Tip: introduce content on how to transfer a patient from the bed to the chair and from the chair to the bed
1	Suggestion: introduce content on how the home environment should be for patient care

In all, eight professionals acted as experts in the booklet validation, six nurses, a nutritionist and a pharmacist. With regard to the qualification of professionals, six are experts in PC and two hold a master's degree in another area of knowledge. Three act as professors, teaching classes related to PC, five are professionals who work directly in assisting patients

under PC. Still, to validate the booklet, 12 target audience representatives participated, mostly children (5; 41.6%), adults (9; 75%), with complete high school (4; 33.3%), without formal employment (9; 75%) and with an income of 2 minimum wages (6; 50%). The items assessed and their respective CVI values are detailed in Table 1.

**Table 1.** Judges' agreement on the booklet items

Item	n(%)	I-CVI *	p-value †
Content			
Content meets a possible caregiver training situation	8(100)	1	1
Titles/subtitles are divided consistently	8(100)	1	1
The highlighted sections deserve to be highlighted	8(100)	1	1
Content meets the target audience's needs	8(100)	1	1
Text has a logical sequence	8(100)	1	1
Content is relevant to caregivers	8(100)	1	1
From a scientific point of view, content is correct	8(100)	1	1
Language			
Wording is compatible with the target audience	8(100)	1	1
Phrases are attractive	8(100)	1	1
Text has clarity and objectivity	8(100)	1	1
Illustration			
Illustrations relate appropriately to content	8(100)	1	1
Illustrations are understandable	8(100)	1	1
Captions help caregivers to understand the image	8(100)	1	1
Number of images is sufficient to address content	8(100)	1	1
Layout			
Font size and font make it easy to read	8(100)	1	1
Colors in the booklet make reading feasible	8(100)	1	1
Arrangement of items on the pages is organized	8(100)	1	1
Number of pages and material size are adequate	8(100)	1	1
Motivation			
Content encourages caregivers to continue reading	8(100)	1	1
The booklet is clear and clarifies caregivers' doubts	8(100)	1	1
Culture			
The booklet is capable of meeting different caregiver profiles	8(100)	1	1

\*Percentage of agreement in the item; I-CVI - Item-Level Content Validity Index; † Binomial test.

The topics “guidelines on contact with domestic animals” and “care for the caregiver” were suggested by three experts as relevant to compose the booklet. The suggestions were accepted and the topics were introduced in the booklet.

With regard to the assessment carried out by the target audience representatives, there was unanimity in the responses of all participants regarding the relevance of items assessed in the booklet, that is, there was 100% agreement in all items assessed. The only suggestion made by a participant was to increase font size. The suggestion was accepted and, with that, the final version was defined.

## Discussion

Currently, there is a preference by patients and their families for PC to be carried out at home. This trend sends the responsibility for care back to families. However, for patients' preference to be met, it is necessary for their families to have a structure for care.<sup>(16)</sup> Facing a patient with numerous needs, a family member/caregiver starts to perform functions that are often unknown to most of them. Therefore, these activities can generate emotional, physical, social and economic stress, negatively impacting their mental health and quality of life.<sup>(17)</sup>

Thus, the use of educational booklets and the availability of manuals in printed or online format allow nursing guidelines to be assimilated beyond the hospital environment, expanding the understanding of information and strengthening learning for care. Additionally, the use of educational materials in health is essential to intensify the guidance provided, being viable instruments with simple language and of great support for home care.<sup>(18)</sup>

Through bibliographic search in national and international literature, it was possible to observe the scarcity of studies on the construction and validation of educational materials aimed at caregivers. In this search, a recent study was carried out in southern Brazil, which aimed to develop a booklet to assist caregivers of patients with incurable disease in the process of guidance regarding main care, symptoms and information capable of mitigating the final moments of life, in order to offer comfort and quality of life to patients. The authors went through a bibliographic search to substantiate the content and construct the booklet itself. However, the material was not validated by experts or target audience representatives.<sup>(19)</sup>

Constructing an educational material aims to contribute to the development of skills, favoring autonomy in the face of activities and decisions of patients and family members.<sup>(20)</sup>

Thus, in the present study, each step taken to reach the proposed objective proved to be fundamental. Associating bibliographic survey about home care, the collection of relevant information and consistent with caregivers' needs was essential

to define the content to be included in the booklet, allowing the material to contribute to offer home care for patients (Figures 1, 2 and 3).

Also, in the validation process, the participation of target audience representatives is important because it allows their opinion on content, language and appearance, allowing the material to be suitable for the population for which it is intended.<sup>(21)</sup> Furthermore, the target audience also points out relevant aspects to be included, as could be perceived in the present study.<sup>(22)</sup>

The option to include photographs related to the booklet's theoretical content was considered more attractive. An adequate illustration of an educational material arouses readers' interest in knowing its contents because its creative forms are linked to an updated scientific evidence.<sup>(23)</sup> Also, adopting a simple and inviting language facilitates the understanding of the contents and the attractiveness of the text.<sup>(24)</sup>

The final step consisted of validating the constructed material. The participation of multidisciplinary team members, and not only of nursing team members, in the body of experts was of great importance for the booklet assessment. In the process of constructing educational materials, the sum

Índice	
1. O que são cuidados paliativos?.....	05
2. Como manter um ambiente doméstico acolhedor e seguro para o meu familiar?.....	05
3. Meu familiar usa sonda nasogástrica/nasoentérica. O que é e como devo manusear?.....	06
4. Como evitar a saída da sonda nasoentérica?.....	09
5. Quando devo procurar o serviço de saúde por problemas com a sonda?.....	10
6. Meu familiar é acamado. Como faço para movimentá-lo na cama?.....	10
7. Como faço para virar o meu familiar de lado na cama?.....	13
8. Como coloco meu familiar na cadeira de rodas/poltrona/sofá?.....	14
9. Como transfiro meu familiar da cadeira de rodas ou poltrona para cama?.....	18
10. Como realizar o banho do meu familiar?.....	20
11. Higiene bucal.....	22
12. Meu familiar tem ostomia. Como devo cuidar? Como devo cuidar da Traqueostomia?.....	22
13. Como limpar a bolsa de colostomia?.....	23
14. Como proteger a pele ao redor da gastrostomia?.....	24
15. É normal me sentir estressado e desanimado? E o que posso fazer para me sentir melhor?.....	24
16. Meu familiar pode ter contato com animais de estimação?.....	26
17. Referências.....	28
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**Figure 1.** Index of “*Eu cuido, nós cuidamos – cuidados domiciliares a pacientes em cuidados paliativos*”



This result corroborates other methodological studies carried out in Brazil. A study that aimed to validate the content of a booklet for caregivers of children with hydrocephalus obtained CVI between 0.9 and 1.0.<sup>(30)</sup> Another study validating a booklet for the prevention of metabolic syndrome in adolescents obtained a CVI of 1.0 in most of the items analyzed.<sup>(31)</sup> Thus, the reach of high rates confirms the adequate validation of the material in terms of content and appearance, as occurred in the present study.

A study limitation is that the material was assessed only by caregivers of patients using the Unified Health System (*Sistema Único de Saúde*) so that the results obtained may differ from the reality of caregivers of patients cared for in the private health care network.

## Conclusion

This study aimed to describe the construction and validation of an educational booklet for PC at home after hospital discharge. The global CVI, achieved in an assessment by experts, and the total agreement between the target audience representatives, confer, respectively, the content and appearance validity of “*Eu cuido, nós cuidamos – cuidados domiciliares a pacientes em cuidados paliativos*”. Through the construction of an educational booklet, caregivers of patients hospitalized under PC will receive the booklet at hospital discharge to assist them in home care. Still, this material will contribute to nurses’ assistance in planning guidelines for hospital discharge, in order to provide autonomy and support to caregivers. In this regard, it is suggested to carry out an application study, as well as to carry out annual reviews of the manual, based on the most current scientific knowledge.

## Collaborations

Silva FRR, Pereira RA, Souza AC, Gimenes FRE, Simino GPR, Dessote CAM, Lettiere-Viana A and Bolela F contributed to the project design, data

analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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