

# Home intravenous infusion: educational technologies for the care of people with hemophilia

Infusão endovenosa domiciliar: tecnologias educativas para o cuidado à pessoa com hemofilia  
 Infusión intravenosa domiciliar: tecnologías educativas para el cuidado de personas con hemofilia

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## Abstract

**Objective:** To develop and validate educational technologies for home care of people with hemophilia on intravenous infusion of clotting factor.

**Method:** This is a methodological study, developed in three stages: development of educational technologies, content and appearance assessment by judges, and appraisal by people with hemophilia. The educational technologies – a booklet and an infographic - were developed through a literature review. In the assessment stage with judges, the Delphi technique was used in two rounds, through Content Validity Index, agreement greater than 0.80 in regarding clarity of language, practical relevance, and theoretical relevance. In the assessment with the target audience, the level of agreement of positive responses greater than or equal to 80% in the items of organization, writing style, appearance and motivation for reading was considered.

**Results:** The booklet presented a global content validity index of 0.88 in the first round and 0.98 in the second; and the infographic, 0.88 in the first round and 0.97 in the second. In the assessment of educational technologies by the target audience, the level of agreement of positive responses was higher than 80%.

**Conclusion:** This study developed educational technologies, a booklet and an infographic, which could contribute to adherence to treatment and promotion of care, by standardizing the guidelines for people with hemophilia in intravenous infusion at home.

## Resumo

**Objetivo:** Elaborar e validar tecnologias educativas para o cuidado domiciliar de pessoas com hemofilia em infusão endovenosa do fator de coagulação.

**Método:** Estudo metodológico, desenvolvido em três etapas: elaboração de tecnologias educativas, avaliação de conteúdo e aparência por juízes e apreciação por pessoas com hemofilia. As tecnologias educativas – cartilha e infográfico – foram elaboradas mediante revisão de literatura. Na etapa de avaliação com juízes, foi utilizada a técnica Delphi em duas rodadas, por meio do Índice de Validade de Conteúdo, concordância superior a 0,80 em relação a clareza de linguagem, pertinência prática e relevância teórica. Na avaliação com o público-alvo, foi considerado o nível de concordância de respostas positivas maior ou igual a 80% nos itens de organização, o estilo de escrita, a aparência e a motivação para a leitura.

**Resultados:** A cartilha apresentou índice de validade de conteúdo global de 0,88 na primeira rodada e 0,98 na segunda; e o infográfico, 0,88 na primeira rodada e 0,97 na segunda. Na apreciação das tecnologias educativas pelo público-alvo, o nível de concordância das respostas positivas foi superior a 80%.

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Conflicts of interest: nothing to declare.

**Conclusão:** Este estudo elaborou tecnologias educativas, cartilha e infográfico, que poderão contribuir com a adesão ao tratamento e promoção do cuidado, por meio de padronização das orientações às pessoas com hemofilia em infusão endovenosa domiciliar.

## Resumen

**Objetivo:** Elaborar y validar tecnologías educativas para el cuidado domiciliario de personas con hemofilia sobre la infusión intravenosa domiciliar del factor de coagulación.

**Métodos:** Estudio metodológico desarrollado en tres etapas: elaboración de tecnologías educativas, evaluación de contenido y apariencia por jueces y valoración por parte de personas con hemofilia. Las tecnologías educativas (cartilla e infográfico) fueron elaboradas mediante revisión de literatura. En la etapa de evaluación con jueces, se utilizó el método Delphi en dos rondas, por medio del Índice de Validez de Contenido, concordancia superior a 0,80 con relación a la claridad del lenguaje, pertinencia práctica y relevancia teórica. En la evaluación con el público destinatario, se consideró el nivel de concordancia de respuestas positivas mayor o igual a 80 % en los ítems organización, estilo de escritura, apariencia y motivación para lectura.

**Resultados:** La cartilla presentó un Índice de Validez de Contenido global de 0,88 en la primera ronda y 0,98 en la segunda. El infográfico presentó 0,88 en la primaria ronda y 0,97 en la segunda. En la valoración de las tecnologías educativas por el público destinatario, el nivel de concordancia de las respuestas positivas fue superior al 80 %.

**Conclusión:** En este estudio se elaboraron tecnologías educativas, cartilla e infográfico, que podrán contribuir con la adherencia al tratamiento y promoción del cuidado, mediante la estandarización de las instrucciones a personas con hemofilia sobre infusión intravenosa domiciliar.

## Introduction

Hemophilia is an X-linked hemorrhagic disorder characterized by the deficiency or absence of clotting factor VIII (hemophilia A) or IX (hemophilia B).<sup>(1)</sup> The clinical presentation of hemophilia A and B is similar, as both are characterized by intra-articular bleeding (hemarthrosis), bleeding in muscles, cavities or other tissues. Therapeutic treatment is based on the administration of clotting factors VIII or IX, which can occur on demand (right after bleeding) or prophylactically. Due to the impossibility of maintaining constant levels of clotting factors in people with hemophilia, these individuals live under the constant threat of unexpected bleeding.<sup>(2)</sup>

Thus, the Brazilian National Program for Hereditary Coagulopathies (*Programa Nacional de Coagulopatias Hereditárias*) provides for intravenous self-infusion by people with hemophilia – or by a family member – whenever there is suspicion of bleeding, trauma or the need to infuse clotting factor prophylactically.<sup>(3)</sup> To do so, people with hemophilia must be registered in a specialized treatment center, participate in a clarification meeting on the insertion in home treatment and training, in order to learn how to apply the factor concentrate by intravenous route as well as having up-to-date laboratory and clinical exams.<sup>(4)</sup>

To assist nurses' work, the Guidelines for the Management of Hemophilia addresses the content of home infusion training, aimed at general knowl-

edge about the disease: identification of hemorrhages; first aid actions; clotting factor reconstitution; aseptic techniques to perform the puncture; infusion diary records; and proper storage of needles and sharp objects.<sup>(5-7)</sup>

In this context, nurses must provide information about nursing care, risks and complications during treatment to people with hemophilia, family members or caregivers.<sup>(8)</sup> However, there is a need for standardization of information as well as the use of educational materials that help in this care.<sup>(9)</sup> Studies on home education programs for this target audience are limited. Although there are educational materials on the subject, few are validated.<sup>(10)</sup>

It is known that the use of printed educational technologies provides the development of skills and mediates knowledge during educational activities. It is a viable alternative to inform and sensitize the population, which contributes to promoting health through popular participation, in a shared construction of knowledge. Moreover, it allows patients and their families a further reading, which reinforces the verbal guidelines given in the nursing consultation, serving as a guide in cases of doubt and assisting in daily decision-making.<sup>(11)</sup>

In this scenario, considering that the incorrect practice of intravenous home infusion represents health risks, as well as implications for quality of life, high costs to public health – and that the lack of educational materials makes it difficult to provide adequate information –, the study is justified

because it develops educational materials aimed at caring for people with hemophilia. To develop and validate educational technologies for home care of people with hemophilia on intravenous infusion of clotting factor.

## Methods

This is a methodological study, carried out from March 2017 to April 2019, developed in three stages: educational technology elaboration, in booklet and infographic formats; content assessment by judges; and appreciation by the target audience. The educational technologies produced in this study are intended for people with hemophilia who undergo intravenous infusion therapy of clotting factor at home.

The development of technologies began with a bibliographic survey, through a literature review, using the following sources: World Federation of Hemophilia (Guidelines for the Management of Hemophilia) guidelines and Ministry of Health recommendations.<sup>(3,5,12,13)</sup>

The methodological framework for creating the educational booklet followed the Moreira, Nóbrega and Silva guidelines, Echer precepts and A Guide to Creating and Assessing Patient Materials guidelines.<sup>(14,16)</sup> As for the Infographic, the methodological framework followed the guidelines of Moreira, Nóbrega and Silva and Carvalho and Aragão.<sup>(14,17)</sup> After listing the relevant content for the materials, a script was prepared with information and texts and, later scientific language adequacy. Then, with the help of a graphic designer, the art was elaborated through the illustrations, configuration and layout of the pages.

The second stage, called content and appearance assessment, was carried out with the aim of verifying whether the exposure of concepts occurred properly, and whether the instrument's texts were representative within the product's universe.<sup>(18)</sup> We chose to use the Delphi technique, which consists of a systematic method of judging information to obtain consensus among judges on a given topic through the application of structured

questionnaires and feedback statistical analysis of each cycle.<sup>(19)</sup> In this study, the use of the Delphi technique occurred in two rounds: the first consisted of initial submission of educational technologies to judges in February 2018; and the second, to resubmission after adjustments made from the first round suggestions in June 2018.

Judges were chosen according to the following inclusion criteria: being a nurse with a minimum degree of specialist and having at least two years of clinical experience in hemophilia. Searching for judges took place by intentional snowball sampling.<sup>(20)</sup> Thus, when a judge met the pre-established eligibility criteria, he was asked to indicate other possible participants, therefore, it was a convenience sample. In this regard, 34 judges were contacted via e-mail, through an invitation letter, among which 11 accepted to participate in the first round of the study by returning the material, within the stipulated period of 15 days. In the second round, these 11 judges again received the material with the suggested modifications; however, only 7 returned the material within 15 days. The four judges who were unable to participate in the second round of the study claimed time was not available.

After consenting to participate in the research, instructions for operationalization, Informed Consent Form, validation instrument, together with the educational booklet and the infographic in digitized versions were delivered to the judges.

The judges assessed the booklet and the infographic, answering an instrument containing questions regarding its characterization and an instrument adapted from Leite and Crestani, consisting of two parts: the first contained items related to the analysis of objectives, structure, presentation and relevance of educational technologies produced; the second part consisted of items that carefully assessed all the subjects present there. For this assessment, a 4-point Likert-type scale was used, ranging from "not at all relevant" to "very relevant", which allows assessing each subtitle of the booklet and infographic based on clarity of language, practical relevance and relevance theoretical. As for the options marked as "nothing" and "not relevant", justifications were

requested and, later, the items were reviewed by the researchers.<sup>(21,22)</sup>

In the analysis of the assessment instrument by the judges, the calculation was based on the Content Validation Index (CVI), adopting as desirable a CVI greater than 0.80.<sup>(23)</sup> Those with a CVI lower than 0.80 could be excluded or modified, as suggested by the judges. The CVI score was calculated through the sum of agreement of items marked as 3 or 4, divided by the total number of responses. For a complete assessment of the booklet and infographic, the sum of all CVI calculated separately was used, dividing them by the number of items in the instrument.<sup>(18)</sup> Data were analyzed and based on the relevant literature on the subject.

The third stage took place through assessment of educational technologies by the target audience in January 2019. All people with hemophilia A and B or parents/guardians of children with hemophilia who underwent intravenous infusion therapy at home participated in this stage, and were waiting for consultation in the waiting room of the outpatient clinic of a Hematology Center, a reference for coagulopathy care in the Southeast. It is worth noting that all people with hemophilia using clotting factor at home receive training in intravenous infusion.

The inclusion criteria adopted were: being 18 years old or older, being registered in the institution's coagulopathies program, being literate and not having a relationship with the researcher. The exclusion criterion adopted was: to present deformity in the upper limbs, caused by chronic hemophilic arthropathy, which would make material assessment impossible. It should be noted that no participants were excluded from this intentional selection.

The target audience who participated in the research signed the Informed Consent Form, received the printed booklet and infographic, together with an instrument composed of items that considered the domains of organization, writing style, appearance and motivation.<sup>(23,24)</sup>

The participant was individually directed to a reserved room in order to start reading the materials. Then, they answered the instruments that con-

tained answers like “yes”, “no” and “I don't know”. During the entire period, the researcher made herself available to clarify any doubts regarding the assessment completion.

Finally, the educational technologies were assessed by two teachers from the language course and a pedagogue from the education course of a public university for proofreading.

For analysis of data judged by the target audience, items with a level of agreement equal to or greater than 80% of positive responses are considered, i.e., those who got “yes”. Those items where the concordance rate was less than 75% were revised.

Data were compiled into a Microsoft® Office 365 spreadsheet program and, after coding and tabulation, analyzed using descriptive statistics.

The study was approved by the Institutional Review Board of the *Universidade Federal do Espírito Santo*, under Opinion 2,428,681, complying with Resolution 466/2012 (CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 79412117.8.0000.5060).

## Results

The results are presented in three distinct stages: development of technologies, assessment by judges and assessment by the target audience.

### Booklet and infographic preparation

The initial version of the booklet consisted of 28 pages, A4 size (210 x 297), entitled “*Aplicando o fator de coagulação em domicílio*”, and divided into 17 subtitles.

After assessment by the judges and appreciation by the target audience, the final version was entitled “*Aplicando o fator de coagulação em domicílio na pessoa com hemofilia*”, having 28 pages, measuring 150x210mm, printed in color on 150g matte glossy paper/m<sup>2</sup>. The content was summarized in 17 subtitles. Figure 1 shows some pages of the booklet.

The initial version of the infographic consisted of 14 instructions, in a numbered sequence, of step-by-step type, for the home infusion of clotting factor,



**Figure 1.** Pages of the final version of booklet “Aplicando o fator de coagulação em domicílio na pessoa com hemofilia”

distributed close to the edges of the material. To facilitate reading and ensure safety during medication preparation, a blank space in the infographic center was allocated, with the following measurements: 47 cm horizontally and 35 cm vertically. After constructing the text and selecting the corresponding figures, it was sent for layout by a graphic designer.

The final version of the infographic kept its initial formatting, containing the 14 step-by-step instructions. However, the recommendations of judges and people with hemophilia for improving educational technology were included.

Infographic “*Campo de autoinfusão*” consists of coated printed material Polyvinyl Chloride (PVC), allowing it to be cleaned with disinfectants without damaging the images and texts. It presents the orientations arranged close to the edges of the material, in a numbered sequence, having the same initial measurements. Figure 2 represents the final version after assessment.



**Figure 2.** Final validated version of infographic “*Campo de autoinfusão*”

### Assessment by judges

Assessment was performed by 11 nurses, in the first round of the Delphi technique. They were predominantly aged between 31 and 40 years (54.5%). Among them are two doctors (18.2%), three masters (27.3%) and six specialists (54.5%). Regarding professional practice, 4 finished college 1 to 10 years ago (36.3%), 3, 11 to 20 years ago (27.3%), two, 21 to 30 years ago (18.2%) and two, 31 to 40 years ago (18.2%). As for length of experience in hemophilia, six judges had between two and five years (54.5%).

For the second round, seven judges (63%) participated, being classified as: ages between 31 and 40 years (57.1%), and all were female (100%). Among them, 2 masters (28.6%) and five specialists (71.4%). Regarding professional practice, 3 finished college 1 to 10 years ago (42.8%), 3, 11 to 20 years ago (42.8%) and 1, 21 to 30 years ago (14.2%). As for length of experience in hemophilia, 6 had between 2 and 5 years (85.7%), and 1 had over 11 years (14.3%).

In the first round, 4 of the 17 subtitles of the first version of the booklet had a CVI of less than 0.80 in relation to clarity of language, practical relevance and theoretical relevance. Thus, 12 suggestions were made for term replacement or exclusion, illustration reformulation, sentence readjustment, among others. These proposals were analyzed and all suggestions accepted based on the relevant scientific literature. Although some subtitles had a CVI greater than 0.80, 34 considerations were made by the judges – such as suggestions for sentence readjustment –, 24 of which were accepted by the researchers. After adjustments, the materials were sent back and, in the second round, all CVIs were greater than 0.80, and only one judge made a new suggestion.

In the assessment of the infographic, of the 14 guidelines analyzed individually regarding clarity of language, practical relevance and theoretical relevance, five had a CVI lower than 0.80, in which seven suggestions for adjustments were made by the judges. After the changes, the infographic was re-submitted and, in the second round, it presented a CVI greater than 0.80 in individual assessments, without new suggestions.

When comparing the CVIs of the first and second rounds of the booklet assessment, we verified that, in relation to objective, all items obtained a CVI greater than 0.80. In the infographic, however, only one item had a CVI less than 0.80 in the first round. As for structure and presentation, CVI was 0.72 in two topics presented, and in the infographic, one topic. Regarding relevance, all items in the booklet and infographic had a CVI greater than 0.80 in the two rounds, according to Table 1.

**Table 1.** Judges' assessment of objectives, structure/presentation, relevance and CVI of the booklet and infographic by item, in the first and second rounds of the Delphi technique

Items	Booklet		Infographic	
	1 <sup>st</sup> Round n=11 CVI	2 <sup>nd</sup> Round n=7 CVI	1 <sup>st</sup> Round n = 11 CVI	2 <sup>nd</sup> Round n=7 CVI
1. Objectives				
1.1 Contemplates the proposed theme	1.00	0.85	0.72	0.85
1.2 Suitable for teaching-learning process	0.90	0.85	0.81	0.85
1.3 Clarifies doubts about the topic covered	1.00	1.00	1.00	1.00
1.4 Provides reflection on the topic	0.90	1.00	1.00	1.00
1.5 Encourages behavior change	1.00	1.00	1.00	1.00
2. Structure and presentation				
2.1 Language suitable for the target public	1.00	1.00	1.00	1.00
2.2 Interactive language, allowing active involvement in educational process	1.00	1.00	1.00	1.00
2.3 Correct information	0.72	0.85	1.00	1.00
2.4 Objective and clarifying information	0.72	0.85	0.81	0.85
2.5 Necessary information	1.00	1.00	1.00	1.00
2.6 Logical sequence of ideas	0.90	0.85	0.72	1.00
2.7 Current topic	1.00	1.00	1.00	1.00
2.8 Proper text size	1.00	1.00	1.00	1.00
3. Relevance				
3.1 Encourages learning	1.00	1.00	0.90	1.00
3.2 Contributes to knowledge in the field	0.90	1.00	0.90	0.85
3.3 Awakens interest in the topic	0.90	1.00	0.90	1.00

n - number of judges; CVI - Content Validity Index

### Appreciation by the target audience

The materials were appreciated by the target audience, represented by 10 people with hemophilia, aged between 33 and 52 years, 8 men and 2 women. Regarding education, 1 (10%) did not complete elementary school, another (10%) completed elementary school, 4 (40%) completed high school, 2 (20%) complete higher education, 1 (10%) had specialization and another (10%) held a PhD.

For the booklet assessment, of the four domains assessed, writing style, appearance and motivation had the highest number of positive responses. The

level of agreement of positive responses ranged from 90% to 100% between the items addressed, totaling 99.2% in general. However, eight suggestions were made regarding organization, writing style and appearance, seven of which were accepted and included in the final version of the booklet.

To assess the infographic, we used the same tool to assess the booklet appearance. Of the four domains assessed – organization, writing style, appearance and motivation – all showed a level of agreement greater than 80% in the positive responses, and only one suggestion.

## Discussion

This research promoted the development and assessment of content and appearance of two educational technologies, which will help people with hemophilia, caregivers and family members to resolve doubts and overcome difficulties in the home context of intravenous infusion of clotting factor. In other words, it will contribute to acting positively in the health-disease process, preventing complications and reducing costs related to the incorrect use of this medication.

Despite advances in electronic means of communication, it was decided to make written materials. This choice is justified by the fact that they are easily accessible materials, without the need for technology, which contributes to the orientation of the population in general, regardless of their socioeconomic level.

The intention of the booklet and the infographic is to provide the construction of knowledge of people with hemophilia through meaningful, capable learning to promote real changes in attitudes. Moreover, the purpose of preparing the infographic is to guide step-by-step, in a guided and summarized manner, as physical support for the materials used during the performance of intravenous infusion at home.

For this reason, nurses, when carrying out their guidelines, can appropriate technological tools to communicate with patients and encourage their interest in learning, in which the use of educa-

tional booklets can integrate patients in the teaching-learning process, making the potential mediators and leaders in the act of caring.<sup>(25,26)</sup> In this context, both the booklet and the infographic produced in this study can develop positive behaviors and increase adherence to prophylaxis, in addition to preventing the worsening of adverse events.

In process of assessing the content and appearance of educational technologies, contributions from judges and assessment by representatives of the target audience were included. Although the overall CVI was satisfactory in the first and second rounds, the judges made suggestions to ensure the best quality of educational materials. Such details contribute to the enrichment of the final product and the improvement of its applicability.<sup>(27,28)</sup>

Therefore, the process of adapting the educational material to judges' suggestions is an essential step to make the technology more complete and with greater scientific rigor. In the booklet assessment, three judges emphasized the need to change the illustrative figures under subtitle "*Você sabe o que é Hemofilia?*". The modifications in the booklet were guided in accordance with the international guidelines, which indicate that the practices of low-impact sports, such as swimming, cycling and dancing are more recommended. Another change in the illustration was related to subtitle "*Descartando o material perfurocortante*", as a judge recommended changing recyclable container's symbol to infecting symbol, thus representing biohazard material.<sup>(5,29)</sup>

We also suggested adding relevant information and improving the writing of topics related to the benefits of home infusion: guidance in case of joint bleeding; care to avoid infection during infusion; clotting factor application; recognition of an allergic reaction; and some tips for transporting the clotting factor. It is noteworthy that the changes were accepted due to technical agreement and relevance in the scientific literature.

Regarding the assessment of infographic's content and appearance, two judges suggested including an illustration to demonstrate the angulation of the scalp being introduced into the vein. In order to facilitate understanding, a representative figure was

inserted, following the guidelines for venipuncture of the Ministry of Health.<sup>(12,13)</sup>

The target audience also appreciated the educational technologies in a positive way, and considered them important for the promotion of knowledge, with rich content combined with clarity, adequate format and explanatory illustrations. Such results are due to the fact that home therapy reduces the number of absences from school and work, increases the freedom to perform leisure activities, as well as promotes greater patient responsibility in relation to the treatment itself and less time of pain, in addition to reducing visits to a treatment center.<sup>(30)</sup>

Thus, it was possible to observe the level of agreement of positive responses between 90% and 100% in the booklet assessment. Of the eight suggestions related to adding information, replacing technical terms and correcting the numerical sequence of topics, seven were accepted. Considering that intravenous self-infusion by people with hemophilia or by family members is conditioned to participation in training,<sup>(4)</sup> the suggestions for replacement of common terms by technical terms are probably due to their familiarization by the target audience.

In assessing the infographic, all domains obtained a 100% agreement level. The only suggestion made by one of the participants was the removal of acronym "CAI" from title "*Campo de autoinfusão (CAI)*", which became "*Campo de autoinfusão*".

Regarding the study limitations, we can mention the intentional selection for convenience, made by the researcher, in relation to location and target audience, which promotes appreciation of items of educational technologies restricted to social and economic aspects of a single region.

## Conclusion

This study elaborated and assessed educational technologies that will contribute to the educational practice of nursing, considering that they are illustrations capable of assisting in acquisition of knowledge, through memorization of care necessary for intravenous infusion of clotting fac-

tor, in addition to standardizing the guidelines given by healthcare professionals to people with hemophilia. The educational technologies developed, assessed and appreciated in this study give reliability to the products, and make them promoters of knowledge, of adherence to treatment and promotion of care, allowing people with hemophilia to be leaders of their own treatment, through greater autonomy for a safe performance of care. It is expected that further research will be developed, assessing their psychological and emotional aspects during home infusion of clotting factor.

## Collaborations

Pacheco CRS, Cançali Primo C, Fioresi M, Sequeira CAC, Nascimento LCN, Lopes AB and Sipolatti WGR collaborated with the study 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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