

CHILD CARE EDUCATIONAL MANUAL WITH GASTROSTOMY: CONSTRUCTION AND VALIDATION

MANUAL EDUCATIVO DE CUIDADOS À CRIANÇA COM GASTROSTOMIA: CONSTRUÇÃO E VALIDAÇÃO

MANUAL EDUCATIVO SOBRE EL CUIDADO DE NIÑOS CON GASTROSTOMÍA: CONSTRUCCION Y VALIDACIÓN

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Submitted on: 2018/02/20 Approved on: 2018/06/22

ABSTRACT

Introduction: the gastrostomy is a procedure in which a catheter is inserted into the stomach through an opening in the anterior abdominal wall. There is a shortage of work focused on guidelines and care with the use of gastrostomy and the influence for family members and caregivers. Goal: to develop and validate an educational manual regarding gastrostomy care with children. **Method:** it was carried out a bibliographical survey for the development of the content of the manual and validation of it, which was conducted with 11 experts based on the *Delphi* technique and with 5 parents and caregivers of children with gastrostomies, measured using the Likert scale. **Results:** the elaborated material was validated by specialists in two cycles through the *Delphi* technique, with the participation of 11 judges in the first cycle and six judges in the second cycle. The absolute agreement percentage of the whole manual reached 97.91%. The lowest value found in the second cycle was 83.3%, with seven of eight questions showing agreement of 100%. The validation with target audience showed a 100% concordance rate and all participants scored three points on the Likert scale for all questions. The validated manual has ISBN (International Standard Book Number) registration number: 978-85-924327-0-6, with 21 pages, eight chapters and 38 simple and accessible figures of speech, addressing topics such as the concept and indication of gastrostomy, home care and the prevention of complications. **Conclusion:** elaborated educational manual of child care with gastrostomy, validated by specialists, by parents and caregivers.

Keywords: Gastrostomy; Nursing Care; Health Education; Validation Studies.

RESUMO

Introdução: a gastrostomia é um procedimento no qual um cateter é inserido no estômago, através de uma abertura na parede abdominal anterior. Há escassez de trabalhos voltados para orientações e cuidados com o uso da gastrostomia e a influência para os familiares e cuidadores. **Objetivo:** desenvolver e validar um manual educativo sobre cuidados com gastrostomia em crianças. **Método:** realizado levantamento bibliográfico para desenvolvimento do conteúdo do manual e validação do mesmo realizada com 11 especialistas com base na técnica de *Delphi* e com cinco pais e cuidadores de crianças com gastrostomias mensurado por meio da escala de Likert. **Resultados:** o material elaborado foi validado por especialistas em dois ciclos por meio da técnica de *Delphi*, com a participação de 11 juízes no primeiro ciclo e seis juízes no segundo ciclo. A porcentagem de concordância absoluta de todo o manual alcançou valor de 97,91%. O menor valor encontrado no segundo ciclo foi de 83,3%, com sete de oito questões apresentando concordância de 100%. A validação com público-alvo apresentou taxa de concordância de 100% e todos os participantes pontuaram três na escala de Likert para todas as questões. O manual validado possui registro em ISBN de número: 978-85-924327-0-6, com 21 páginas, oito capítulos e 38 figuras de linguagem simples e acessível, abordando temas como o conceito e indicação da gastrostomia, o cuidado domiciliar e a prevenção de complicações. **Conclusão:** elaborado manual educativo de cuidado da criança com gastrostomia, validado por especialistas e por pais e cuidadores.

Palavras-chave: Gastrostomia; Cuidados de Enfermagem; Educação em Saúde; Estudos de Validação.

How to cite this article:

Lima PS, Blanes L, Ferreira LM, Gomes HFC. Child care educational manual with gastrostomy: construction and validation. REME – Rev Min Enferm. 2018[cited _____];22:e-1123. Available from: _____ DOI: 10.5935/1415-2762.20180068

RESUMEN

Introducción: la gastrostomía es un procedimiento por el cual se inserta un catéter en el estómago a través de una abertura en la pared abdominal anterior. Hay escasez de trabajos que tratan sobre los cuidados con la gastrostomía y su influencia en familiares y cuidadores. **Objetivo:** desarrollar y validar un manual educativo sobre los cuidados con la gastrostomía en niños. **Método:** el contenido del manual fue elaborado a partir de un relevamiento bibliográfico y la validación del mismo fue efectuada con 11 especialistas a través de la técnica de Delphi y con 5 padres y cuidadores de niños con gastrostomía mensurado por medio de la escala de Likert. **Resultados:** el material elaborado fue validado por especialistas en dos ciclos según la técnica de Delphi, con la participación de 11 especialistas en el primer ciclo y seis en el segundo ciclo. El porcentaje de concordancia absoluta de todo el manual llegó al valor de 97,91%, el menor valor encontrado en el segundo ciclo fue de 83,3%; en siete de ocho cuestiones hubo concordancia de 100%. La validación con el público objeto presentó un índice de concordancia de 100%; todos los participantes adjudicaron puntaje 3 en la escala de Likert para todas las cuestiones. El manual validado está registrado en el ISBN bajo el número: 978-85-924327-0-6, cuenta con 21 páginas, 8 capítulos y 38 figuras de lenguaje sencillo y accesible, enfoca temas tales como concepto e indicación de la gastrostomía, cuidados domiciliarios y prevención de complicaciones. **Conclusión:** se trata de un elaborado manual educativo de cuidados para niños con gastrostomía, validado por especialistas y por padres y cuidadores. **Palabras clave:** Gastrostomía; Atención de Enfermería; Educación en Salud; Estudios de Validación.

INTRODUCTION

Gastrostomy is a procedure in which a catheter is inserted directly into the stomach through an opening in the anterior abdominal wall. This procedure can be performed surgically, radiologically or endoscopically and currently reports of procedure guided by computed tomography.^{1,2}

The modern devices for gastrostomy are made of silicone or polyurethane, with thin and flexible walls, that are numbered and they are two-way, that facilitate the irrigation and the administration of medicines. They can remain in the patient for a long time, and it is necessary the exchange, only when operating problems occur.³

A systematic review of gastrostomies in children with cerebral palsy reveals that gastrostomy feeding has a negative impact on the families.⁴

Parents of children with gastrostomy express fear as one of the feelings experienced after the placement of the device, highlighting: fear of the probe falling, or the chance that the child has to pluck the device, the balloon can burst, among others.

The performance of the health team in the guidelines for home care is evaluated as inefficient, when caregiver education is improved, an improvement in care outcomes is obtained.^{5,6} Therefore, the present study aims to construct and validate an educational manual on caring for children with gastrostomy.

METHOD

Descriptive and exploratory study of the development and validation of a manual for the care of children with gastrostomy, as a focus for the lay public: parents and caregivers of children with gastrostomies. The stages of realization were the following ones: construction and validation.

The literature describes the development of manuals as a tool for health education and emphasizes the importance of the construction of the content, based on the literature and

the validation of this instrument. It also recommends that the validation is performed by a group of specialists and also by individuals or group of patients with this disease, in the event addressed. He states that the use of informative manuals is one of the strategies that can be used to facilitate the work of the multidisciplinary team in the orientation of patients and families in the process of treatment, recovery and self-care.⁷

The study was approved by the *Comitê de Ética em Pesquisa-CEP* of the *Universidade Federal de São Paulo - UNIFESP* - opinion number: 1.899.234 from CAAE (Presentation Certificate for Ethical Appreciation) 62552416.8.0000.5505. There was also the approval of the *Comitê de Ética em Pesquisa da Associação de Assistência à Criança Deficiente (AACD)*, participating institution, opinion number: 1,902,516 CAAE: 62552416.8.3001.0085.

Initially, an anteriority search was made on the Internet aiming at the research of manuals that have gastrostomy as the central theme, being found only a booklet of institutions focusing on nutrition and dietetics, business manuals who market enteral diets with a focus on orientation at the time of food administration. No device manipulation guidelines were found, skin care, and action in case of complications for the lay public.

For the construction of the manual and content development, a bibliographic survey was carried out in the following databases: PUBMED, LILACS and SCIELO. The descriptors used were: gastrostomy, nursing care and health education, and 33 articles were found in PUBMED databases and 19 in LILACS and SCIELO databases. We selected only the articles that focus on gastronomy care in children, excluding those that deal with another age group. In the national journal of nursing specialty in stomal therapy, using the descriptor of gastrostomy, 12 scientific productions were found, selecting five of them. Only four were specific for the pediatric public and one specific for health education of home gastrostomy care.

The search period occurred from September to November 2016. The thorough reading of the literature subsidized the development of the contents of the manual. The handwriting

of the manual was first written in the Word 2013 (word processor) for elaboration of the prototype and then was sent to a specialized professional in the subject, for the drawing of illustrations and figures. The developed content was structured by chapters with the main information for the care of gastrostomy in children. Manual chapters: Definition - What is gastrostomy? When is gastrostomy indicated?; Caring for gastrostomy at home; Care in food administration and medication; Daily care with peristaltic skin; Emergency situations with gastrostomy - what to do ?; Myths and truths; and Multiprofessional Team.

The *Delphi* technique was adopted, for validation with professionals. This technique has been used in the research in several areas of knowledge, such as in nursing.⁸ It is the method of obtaining opinions and criteria from a group of experts on a topic, using questionnaire applications, but in each phase, pieces of information are used from the previous phases, in search of consensus among the experts.⁹ The selection of the specialists was made by non-probabilistic sampling of convenience type, that is, the researcher selects the elements of a sample he has access to, assuming that they can represent a universe.¹⁰

Selection criteria of experts:

- stomatotherapist nurses and / or;
- nurses with more than two years working with patients with gastrostomies and / or;
- other health professionals with experience in gastrostomies: gastro-pediatric surgeon; endoscopist; speech therapists and nutritionists and / or;
- professionals with specialization in the area of health education;
- to agree to participate in the study and sign in the Informed Consent Form.

For this study, the questionnaire was formulated by the author with closed questions and contained five alternative of answers, with one answer for each question, as follows: 1 = inadequate (I); 2 = partially adequate (PA); 3 =adequate (A); 4 = totally adequate (TA) and 5 = not applicable (NA). These terminologies were used in adaptation to studies in Brazil for manual validation criteria.^{10,11} It was also created, a space for comments under each question, where the expert could write his considerations and notes. The questions that were elaborated for the questionnaire were divided into three parts. The first part contained questions of identification of the professional, as well as area of activity, time of experience and titration. In the second part, some questions were elaborated with the objective of evaluating the presentation of the manual, trying to identify if the illustrations made the theme more understandable, as well as whether the choice of font and colors, adequately organized the manual and whether the number of pages represented the content required for information, to be transmitted. Concerning the third part, the questions sought

to identify the contents of the manual, approving the scientifically correct information, appropriate language, if they represented the central theme to be worked on with the target audience and whether it was appropriate for the use by health-care professionals in their patients.

The questionnaire and the TCLE (Informed consent form) were sent by e-mail through forms, created by means of Google Docs, a free tool with easy and versatile access. This tool allows different forms of use, such as simple questionnaire, registration form, opinion survey, poll, etc. In addition, it can be easily shared by E-mail or directly in the link, which makes this resource a very interesting option for teachers, students, researchers and professionals. It was stipulated the deadline of 15 days for the return of the experts' answers, whose work involves the application of questionnaires.

As for the method for calculating the agreement between judges, it was chosen the method of percentage of absolute agreement (percentage of absolute agreement). It consists solely of calculating the number of times, in which the evaluators agreed and divide by the total number of evaluations (it ranges from 0 to 100%). The value of 75% is considered the minimum of acceptable agreement; but the values from 90% are considered high. A disadvantage of this technique is that it does not take into account the proportion of agreement due to the random.¹² The researchers in this study defined the value of 80% for acceptable agreement.

Likert scale was adopted for validation with the target audience. Parents and caregivers were invited to participate in the research and five caregivers / parents approached, they agreed to participate after reading, clarifying the research goals and signing the TCLE (Informed consent form). The data collection was performed during the visits to the Stomatherapy service in the *Associação de Assistência à Criança Deficiente* (AACD). Participants were randomly selected. For parents / caregivers, it was adopted a three-point Likert scale, so that they evaluated the understanding of the manual as a whole and of each of the chapters. The three points of the scale that were elaborated by the researcher included: one (1) totally inadequate, two (2) partially adequate and three (3) totally adequate.

Selection criteria of the target audience:

- Literate parents and caregivers without visual impairment and / or cognitive deficit.
- To agree to participate in the study and sign the Informed Consent Form.

The validation questionnaire of TCLE (Informed consent form) were delivered personally to parents and caregivers, in a Word document, printed on A4 sheet. After the reading and explanation of the manual, the evaluation of the answers was also calculated from the percentage method of absolute agreement for validation.

RESULTS

The content of the manual developed, was structured by chapters with the main information regarding care with gastrostomy issues in children, after meticulous reading of the national and international studies found in the bibliographic survey.

The text has been described in accessible language, seeing that the manual is intended for parent guidance and/or caregivers of children with gastrostomy. The adequacy of the language aimed to make the content attractive and understandable.

The elaboration of the illustrations and the graphic design were adopted with the intention of arousing more interest and understanding by the reader and characterize the pediatric universe. This phase was carried out with the help of a drawing specialist. The construction of graphic design, was performed after meetings, and was discussed the composition of colors, cover feature, approval of illustrations, format and font size.

To initiate the validation of the manual, some invitations were sent with TCLE (Informed consent form), questionnaire and a copy of the manual, via electronic mail for each selected specialist. Fifteen professionals were invited to participate in the study; 12 returned the e-mail to participate as an appraiser in accordance with the terms of the TCLE (informed consent form), but only 11 returned with the questionnaire answered and with their considerations in the first cycle of *Delphi*. In the second cycle, the questionnaires were re-sent to the same specialists who participated in the first cycle, together with the second version of the manual with corrections and considerations suggested by them. In this phase, only six professionals returned the e-mail with the questionnaire answered, within the stipulated time of 15 days.

The *Delphi* technique allows to carry out some sessions of evaluation for new judgment in order to reach consensus. In the present study, it was possible to obtain consensus in the first cycle, with a high agreement rate among the specialists. The values were above the rate defined by the researchers of the present study. The absolute agreement percentage of the entire manual reached 93.18%. The lowest value found in the first cycle was 81.8%, with four of eight questions, showing agreement of 100% (Table 1).

In order to answer the professional notes and comments, the researchers of the present study opted by carrying out a new validation cycle, previously making the adaptation of the manual, according to the judges' suggestions. Activities were carried out with the counselors and each questionnaire was individually verified and incorporated into the pertinent suggestions, presented by each evaluator. Regarding the appearance of the manual, the suggestions of the experts that have been accepted and are related to the best understanding of the illustrations, such as caption creation and a better device definition. Images were suggested to provide identification with the target audience. Regarding the content of the manual, many experts

were concerned with technical terms, that the first version featured and there were also some suggestions for small additions of information, regarding the chapter on diet management.

Table 1 - Validation by specialists -- 1st *Delphi* Cycle

Questions	% of absolute agreement
Presentation of the manual	
1 - The illustrations are expressive and sufficient to facilitate the understanding of the content.	90.9
2 - The source and size of titles and topics, organize clearly the chapters.	100
3 - The number of pages corresponds to the need of the information.	100
Content of the manual	
1 - The messages are presented in a clear and objective way.	100
2 - The information is scientifically correct.	90.9
3 - The material has adequate language to the target audience, that was proposed.	81.9
4 - The themes reflect the key aspects that need to be worked with the target audience.	100
5 - The manual contains necessary information to be used by the health professional in his educational activities.	81.8
Total percentage of absolute agreement.	93.18

The questions that received ratings 2 = partially adequate and "not applicable" returned to the experts in the second session of evaluation. There were no questions with 1 = inadequate rating. In the second cycle, only four questions were re-submitted, and the number 1 was related to the appearance of the manual and questions 2; 3 and 5 concerning the contents of the manual. The evaluations received in the second cycle of the questionnaire application, achieved an even higher agreement rate, of 97.91%. The lowest value found in the second cycle was 83.3%, with seven of eight questions, showing agreement of 100% (Table 2).

The validation with parents and caregivers of children with gastrostomy, was done through a questionnaire with closed questions of simple language during the research period, during consultations at the co-participating institution.

The co-participating institution *Associação de Assistência à Criança Deficiente* (AACD) has an outpatient department of the specialty of gastropediatrics that serves weekly children with cerebral palsy, among other syndromes, where it was possible, during the visits of the Stomatherapy service, to approach to caregivers and parents for research participation, with five caregivers / parents that were approached and to participate in the research, according to the TCLE (informed consent form). The manual was presented by the researcher and then the manual was given to the evaluator for reading. After the reading was

finished, it was delivered the questionnaire in which the evaluator scored the questionnaire, according to the scale Likert type 1 - not (totally inappropriate). 2 - partially (partially adequate) and 3 - yes, (fully adequate).

Tabela 2 - Validation by specialists 2nd Delphi Cycle

Questions	% of Absolute Agreement
Presentation of the manual	
1 - The illustrations are expressive and sufficient to facilitate the understanding of the content.	83.3
2 - The source and size of titles and topics organize clearly the chapters.	100
3 - The number of pages corresponds to the need of the information.	100
Content of the manual	
1 - The messages are presented in a clear and objective way.	100
2 - The pieces of information are scientifically correct.	100
3 - The material has appropriate language to the proposed target audience.	100
4 - The themes reflect the key aspects which must be worked with the target audience.	100
5 - The manual contains necessary information to be used by the health professional in his educational activities	100
Total percentage of absolute agreement	97.91

With this audience of evaluators the agreement rate was 100%, all participants scored 3 - yes (fully appropriate) on the Likert scale for all issues, without disapproval or par-

tial approval, and also there were no suggestions, only comments of gratification.

Educational manual was titled as: Manual of Care for the Child with Gastrostomy, composed of 21 pages, eight chapters and 38 figures, simple language content for better understanding of the audience that is intended to achieve, with ISBN (International Standard Book Number) registration number: 978-85-924327-0-6 (Figures 1 and 2).

DISCUSSION

The “Manual of Care for the Child with Gastrostomy” was elaborated with the purpose of welcoming and orienting family members and caregivers of children who for various reasons undergo gastrostomy and need to live together and care for this gastric stoma. It is hoped to provide the health professional with teaching materials to work with this audience, making more attractive and understandable, the time of education and guidance.

Several authors have used the strategy of constructing educational technologies, to guide patients in different areas of health care. It was then decided to prepare a manual, because it is considered a technology, although simple, it is capable of reaching more people. The development and implementation of educational technologies, may favor behavioral changes, making the client confident to perform certain health promoting conduct. Among the technologies, it is highlighted the educational manual, which assists in the memorization of contents and contributes to the direction of health education activities.¹³

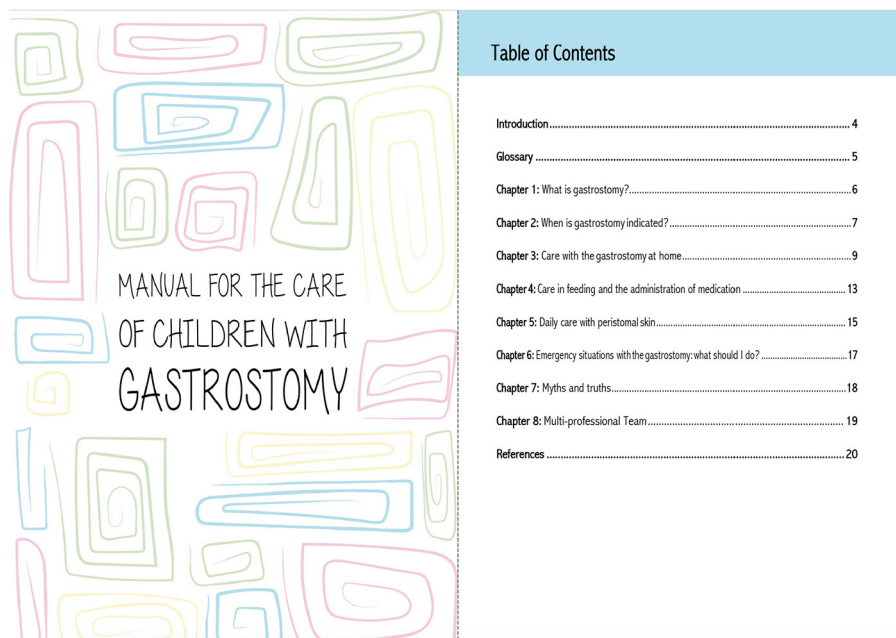


Figure 1 - Manual of Care for the Child with Gastrostomy.

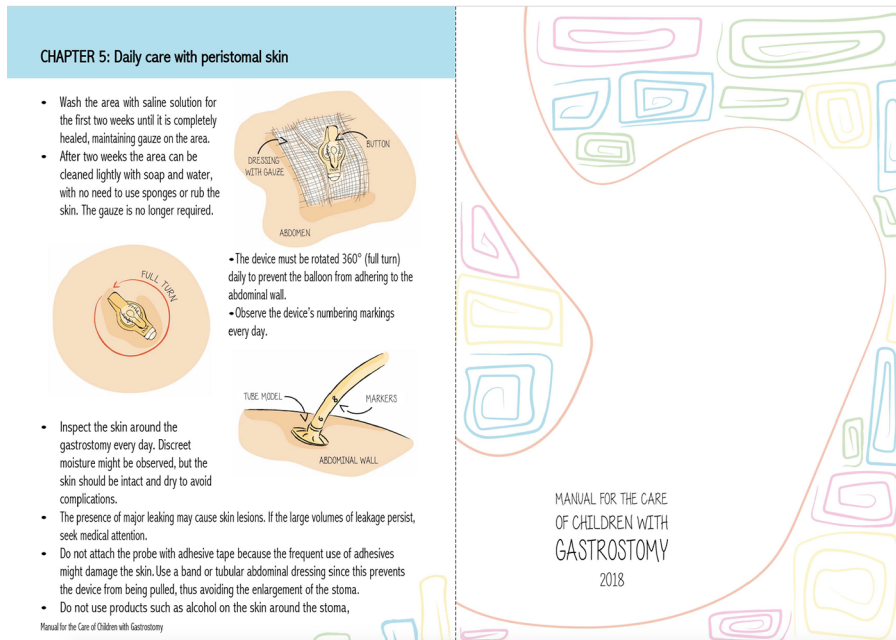


Figure 2 - Manual of Care for the Child with Gastrostomy.

Several authors have used the *Delphi* technique for content validation of their study.^{14,15}

Although a methodology widely used for validation, presents some disadvantages observed during this study. The main ones detected were delay of the process to receive the answers of the specialists, the requirement of the involvement of the expert participant to follow the research and the dropout rate of the participants who, in this study, were 50% between the first and second session, these limiting data have also been reported in the literature.¹⁰

In the validation phase with the target audience, it was identified in this study that all participants scored as a response to the questionnaire applied, a complete understanding of the content, classified as entirely appropriate. Other validation studies with the target audience also positively evaluated this population, with high concordance rates.^{13,16}

In research, authors have identified that the schooling of participants may be related to this result, reporting that only participants who are college graduates, registered suggestions for and improvements to the contents of the manual in the validation process. The level of education of the evaluators of the target public of this study, was similar to that one reported in the literature.¹⁷

In a validation study with target audience, researchers used recorded interviews with open-ended questions. The answers were transcribed and it was analysed afterwards. It was possible to identify a bigger quantity of suggestions, of non-comprehension reports that were provided by qualitative and non-quantitative analysis.¹⁸ A reflection regarding the validation method with this population becomes relevant. The choice of

method and the number of parents and caregivers addressed, represented a limiting factor in the present study.

The theme developed in this manual has few national publications, that's why it is an instrument that seeks to present in a simple and practical way the main content to work with families and caregivers of children with gastrostomy.

In chapter one, by means of figures and concise text, the concept of gastrostomy was approached; the figures exemplified the stomach before and after gastrostomy. For chapter two, a larger text was inserted to explain the indication of gastrostomy, to address issues such as dysphagia, anatomy, diseases involving the indication and benefits of gastrostomy to the child's health, these concepts of several authors that were transformed into plain text.¹

A character portrayed as a health professional maintains a dialogue in chapter three, with the goal of bringing parents closer to health professionals. In this chapter the guidelines of home gastrostomy care are started, presenting the types and models of devices. Chapter number four continues the device handling information at home, working on the main concepts of feeding and drugs administration that were detected, after reading a bibliographical survey.¹⁹⁻²³

Cutaneous complications with gastrostomy have a space in chapter five, where skin care was studied, focusing on the prevention of these complications according to the main recommendations found in the literature.²⁰⁻²³

The accidental exit of the device gains a single chapter, number six, due to the observation of the literature of being a complication with a great impact on home care.^{19,22}

In chapter seven, it was aimed to reduce the myths that involve the care with gastrostomy, to clarify doubts and strengthen true concepts with a very popular language for an accessible reading, as the literature explains concerning this subject.⁷

Chapter eight is the finalization, in which it presents to the reader who the professionals are and what their attributions that can help this family and caregivers in the care of the child with gastrostomy, aiming to give hospitality to this public, as the authors explain concerning this subject.¹⁹

It is hoped that this technology can be used as an alternative to health education for ordinary people who live the reality of gastrostomy, promoting reception. The empowerment of home care generates financial impact directly on the reduction of treatment costs of cutaneous complications, reduction of readmissions and search for emergency services.

This manual may be used in education programs and preparation for patients' de-hospitalization and thus to promote a closer relationship between family members and health professionals. The promotion of a less dull and uninteresting education environment provides quality of life for children and families and, consequently, social inclusion and then stimulates the reflection of society to change public policies.

CONCLUSION

The educational manual was validated, according to content and appearance, by expert judges and also by parents and caregivers. The construction of the educational manual was based on scientific knowledge, available in the literature, as well as the suggestions of the participants, who contributed to the preparation of the final version of this manual. The Gastrostomy Child Care Manual can be used in all health institutions, hospitals that serve pediatric patients with gastrostomy. It is hoped that this study can be an incentive for new researches regarding health education of patients with gastrostomies in the national literature and that other forms of content exploitation may emerge, such as: e-books, protocols, applications, virtual reality, among others.

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