Elaboration and Appraisal of a Booklet on Care for Safe Eating at an Oncology Palliative Care Clinic

doi: https://doi.org/10.32635/2176-9745.RBC.2023v69n2.3757

Elaboração e Avaliação de uma Cartilha sobre os Cuidados para Realizar uma Alimentação Segura na Clínica de Cuidados Paliativos Oncológicos

Elaboración y Evaluación de Cartilla de Cuidados para una Alimentación Segura en la Clínica de Cuidados Paliativos Oncológicos

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ABSTRACT

Introduction: Palliative care is an approach that seeks to understand and help patients who have life-threatening comorbidities. The palliative speech therapist acts in the interaction between patient and family through the rehabilitation of communication and maintenance of oral feeding. Keeping patients, caregivers and the health team informed about care with nutrition and prevent the risk of bronchoaspiration is extremely important, and the utilization of printed materials, such as educational booklets, are great allies in health education. Objective: To develop and evaluate an educational booklet on care for safe eating for caregivers of patients in palliative care. Method: A field survey was carried out with the participation of ten caregivers/companions of patients in palliative care and ten health professionals from an oncology hospital who work in palliative care clinics. For the evaluation of the proposed booklet, all participants responded to a questionnaire addressing topics as comprehension, language utilized, understanding of food care, among other relevant information to their evaluation. Afterwards, descriptive statistics was performed to treat the data obtained. Results: The average approval of the booklet by the group of health professionals was 9.65 and by caregivers/companions, 10.00. Conclusion: The booklet entitled "Care guide for safe eating" was highly approved by the public investigated and considered valid to be adopted by the population.

Key words: neoplasms; palliative care; feeding behavior; deglutition disorders; health education.

RESUMO

Introdução: Cuidados paliativos são uma abordagem que busca compreender e auxiliar pacientes com comorbidades que ameaçam a vida. O fonoaudiólogo paliativista atua na interação entre paciente e familiar por meio da reabilitação da comunicação e manutenção da alimentação por via oral. Manter os pacientes, cuidadores e a própria equipe de saúde informados sobre os cuidados com a alimentação e prevenção do risco de broncoaspiração é de extrema importância, e a utilização de materiais impressos, como cartilhas educativas, é uma grande aliada na educação em saúde. Objetivo: Elaborar e avaliar uma cartilha educativa sobre os cuidados para realizar uma alimentação segura para cuidadores de pacientes em cuidados paliativos. Método: Pesquisa de campo com a participação de dez cuidadores/acompanhantes de pacientes em cuidados paliativos e dez profissionais de saúde de um hospital oncológico que trabalham nas clínicas de cuidados paliativos. Para a avaliação da cartilha proposta, todos os participantes responderam a questionários que continham perguntas referentes ao entendimento, linguagem utilizada, compreensão dos cuidados com a alimentação, entre outras informações pertinentes para sua avaliação. Em seguida, realizou-se a estatística descritiva para tratamento dos dados obtidos. Resultados: A média de aprovação da cartilha foi de 9,65 para o grupo de profissionais de saúde e 10,00 para os cuidadores/acompanhantes. Conclusão: A cartilha intitulada "Guia de Cuidados para Realizar uma Alimentação Segura" obteve alta aprovação pelo público pesquisado e foi considerada válida para ser utilizada pela população.

Palavras-chave: neoplasias; cuidados paliativos; comportamento alimentar; transtornos de deglutição; educação em saúde.

RESUMEN

Introducción: Los cuidados paliativos son un abordaje que busca comprender y ayudar a los pacientes que presentan comorbilidades que amenazan su vida. El fonoaudiólogo paliativo actúa en la interacción entre paciente y familia mediante la rehabilitación de la comunicación y el mantenimiento de la alimentación oral. Mantener informados a los pacientes, cuidadores y al equipo de salud sobre los cuidados con la nutrición y la prevención del riesgo de broncoaspiración es de suma importancia, y el uso de materiales impresos, como cartillas educativas, es un gran aliado en la educación en salud. Objetivo: Desarrollar y evaluar una cartilla educativa sobre cuidados para realizar una alimentación segura para cuidadores de pacientes en cuidados paliativos. Método: Se realizó una encuesta de campo con la participación de diez cuidadores/acompañantes de pacientes en cuidados paliativos y diez profesionales de la salud de un hospital oncológico que laboran en clínicas de cuidados paliativos. Para la evaluación de la cartilla propuesta, todos los participantes respondieron cuestionarios que contenían preguntas sobre comprensión, lenguaje utilizado, comprensión del cuidado con la alimentación, entre otras informaciones relevantes para su evaluación. Después, se realizó estadística descriptiva para el tratamiento de los datos obtenidos. Resultados: El promedio de aprobación de la cartilla fue de 9,65 para el grupo de profesionales de la salud y de 10,00 para los cuidadores/ acompañantes. Conclusión: La cartilla titulada "Guía de cuidados para una alimentación segura" fue altamente aprobada por el público encuestado y considerada válida para su uso por la población.

Palabras clave: neoplasias; cuidados paliativos; conducta alimentaria; trastornos de deglución; educación en salud.

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INTRODUCTION

Population aging has brought with it an increase in chronic non-communicable diseases that include groups of pathologies such as: cardiovascular diseases, chronic respiratory diseases, diabetes and cancer, comorbidities that require long-lasting and specific care¹. Palliative care for these comorbidities can be performed concomitantly or not with curative therapies, depending on the stage of the disease in which the subject is, acting to control symptoms, in order to minimize them. In this modality of care, a holistic vision is implemented that covers the human being in a biopsychosocial and spiritual way, intervening in a preventive way and in the control of the symptoms of life-threatening diseases¹.

In the context of palliative care, the speech therapist is essential in the multidisciplinary team, as he contributes to the integral care of care, intervening in complications and sequelae related to the underlying disease and treatments. Its role is to act in the conviviality and interaction between patient and family through the rehabilitation of communication and maintenance of oral feeding, guaranteeing safety, independence and pleasure during the act of feeding and minimizing the risks of bronchoaspiration, also intervening in the needs of self-care, comfort and autonomy of the individual².

The speech-language pathologist aims to undertake a safe and satisfactory diet, with conducts such as: adequacy of the feeding route, supply volume, rhythm, posture and adequate utensil to carry out the intake, always respecting the wishes of the patient and their caregivers and/or responsible family members³.

In the palliative care clinic, food has a symbolism for patients and their families, as it represents life and health, directly influencing emotional, affective and social aspects, and may suffer great impacts during the treatment of the disease. Feeding suffers several losses: inability to taste, smell, difficulty in digesting food and in the absorption of nutrients and swallowing, which can transform the meal into a moment of stress and discomfort, leading the patient to obtain consequences such as inappetence, weight loss and malnutrition⁴.

Among the set of symptoms related to feeding difficulties, there is dysphagia, characterized as any difficulty in swallowing food, which can happen from the mouth to the stomach, leading to an impairment in the quality of life of the individual and bringing complications such as aspiration pneumonia, dehydration, malnutrition and social impact, such as isolation⁵.

Regarding the risks of bronchoaspiration, speech therapy initially occurs in a preventive manner, with guidance on the importance and need to perform daily oral hygiene, adjustments in diet consistency according to the needs of each patient, and bedside positioning at 45° to avoid possible complications with oral intake⁶.

Preventive measures, especially in the hospital environment, are extremely important, and speech therapy helps to prevent the risks of bronchoaspiration and the incidence of dysphagia, reducing the occurrence of aspiration pneumonia, increased length of stay and hospital costs⁷.

Keeping patients and caregivers informed of the difficulties and risks throughout the illness is important, as it adds them to the care process, as well as keeping an informed professional team is highly relevant in this context. Therefore, applying permanent health education strategies, using printed materials to propagate the recommendations, is of great value⁸.

Printed materials, such as posters, pamphlets, and booklets, among others, have the objective of disseminating important content for prevention, favoring the ideal standard of health, reinforcing guidelines passed on orally, and contributing to the implementation of care during treatment by the individual himself.

The educational booklets were created in order to promote access to information by people from different social classes and levels of education. The booklets used to promote health promotion seek an attempt to bring the world of science closer to the lay public, using strategies such as: 1) images and graphic resources that facilitate the understanding of all audiences, even those who are poorly educated or have difficulty reading; 2) the didactics of information: short sentences, common sense vocabulary and slang; 3) the combination of the two previous items: use of images and text with easy-to-understand language¹⁰.

Everyone has the right to knowledge, regardless of the means used, these health education strategies should be used at all levels of complexity, contributing to the promotion of health, quality of life and seeking the earliest possible care when necessary.

Based on the importance of health education, the research carried out aimed to develop and evaluate an educational booklet to carry out safe eating and prevent the risks of bronchoaspiration for caregivers of patients in palliative care.

METHOD

Field research with the participation of ten caregivers/ companions of patients in palliative care and ten health professionals from an oncology hospital who work in palliative care clinics. For the evaluation of the proposed booklet, all participants answered questionnaires that contained questions regarding understanding, language

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used, understanding of food care, among other relevant information for their evaluation. Then, descriptive statistics were performed to treat the data obtained.

The first stage of the research was based on a bibliographic review in the *Google* Scholar, SciELO and lilacs databases, using the following descriptors: palliative care; eating behavior; dysphagia; and health education. To choose the literature that would be useful for the construction of this work, the abstracts were first read and, when a strong relationship was identified with the object of the research undertaken, it was selected both to subsidize the formulation of the first version of the booklet called "Care Guide for Safe Eating" and for the construction of the bibliographic reference present in this article.

For the preparation of the booklet, the role of the speech therapist in palliative care was briefly addressed, in addition to the guidelines on care to carry out the feeding, divided into the topics: posture, quantity, time between offers, chewing, swallowing, oral hygiene, focus on attention, oxygen and food support, comfort diet, zero diet, care in the feeding of the tracheostomized patient, care in the feeding of the patient with alternative feeding route, attention, and reference.

The booklet evaluation process took place in the Oncology Palliative Care Clinics (OPCC I and II) of the Ophir Loyola Hospital, with the participation of caregivers/companions, and health professionals working in the respective clinics. The following inclusion criteria were used: caregivers of hospitalized patients under palliative care who could read and write, as well as clinic professionals who agreed to participate in the research. And as exclusion criteria: caregivers of patients who were not assisted by the palliative care team, who could not read and write, and also professionals who did not work in the respective wards and/or did not grant their participation. This stage took place from August to November of 2022.

After applying the inclusion and exclusion criteria, 20 participants were selected, divided into ten health professionals and ten caregivers/companions. Health professionals were comprised of: Physician (1), nurses (2), nursing technicians (2), psychologist (1), physiotherapist (1), nutritionist (1), occupational therapist (1) and speech therapist (1).

To enable participants to evaluate the booklet, two questionnaires were applied, one with health professionals and one with caregivers/companions, who were the judges of the content analysis addressed in the booklet. For the evaluation of the proposed booklet, all participants answered questionnaires that contained questions regarding understanding, language used, understanding of food care, among other relevant information for their

evaluation. Data extracted from the data collection instruments were tabulated and analyzed by descriptive statistics.

Even after the high acceptability of the first version of the booklet, the opinions of the participants of this research were taken into account and, therefore, adjustments were made with regard to the adequacy of the language and the additions of illustrations, in order to improve the educational material and reach a large scale audience. The booklet was submitted to the *Canva* and *Adobe Photoshop* programs for standardization and preparation of the final version.

This project was submitted to Plataforma Brasil and to the Research Ethics Committee of Hospital Ophir Loyola, obtaining its approval under opinion number 5.563.646 (CAAE: 58082322.4.0000.5550). This research considered the precepts of the Declaration of Helsinki and the Nuremberg Code, respecting the resolutions related to the Research Standards Involving Human Beings, such as the Resolution of the National Health Council (CNS) no. 466/12¹¹. All participants signed the Informed Consent Form (ICF).

RESULTS

Based on the extracted data, the results are separated by both groups surveyed, shown in Tables 1 and 2.

DISCUSSION

The preparation of the booklet (Figure 1) occurred due to the need to disseminate information regarding precautions with the intake that caregivers or companions of patients in palliative care should take, considering that they are mainly responsible for putting into practice the guidelines passed on by the health team, as well as, even without presenting technical knowledge, they manage various aspects of the patient's life, for example, hygiene care, medication supply, and food¹².

Therefore, the face and content validation process and the evaluation of the applicability of this health education material occurred through questionnaires (Tables 1 and 2), in which the first question made to both participating groups refers to the understanding of the contents presented in the booklet, in which 100% of the participants said they discerned the data exposed in the material.

Regarding the language used, 100% of the participants in the group of caregivers/companions reported easy understanding, while in the group of health professionals, 90% reported the same, and 10% pointed out that it is not an easily accessible language for all audiences.

Table 1. Analysis of the data contained in the questionnaire applied to the health professionals group

Questions of the questionnaire	Yes %	N	No %	N	Average Acceptance
1.1 After completing the reading of the booklet, can you understand the proposal and the contents that were addressed in it?	100%	10	0%	0	-
1.2 Was the language used easy to understand for all social classes found in the hospital?	90.00%	09	10.00%	01	-
1.3 Was any information found in the booklet difficult to understand? If so, which one?	20.00%	02	80.00%	08	-
1.4 Does the care information described in this primer make it easier to understand what to do about food care?	100%	10	0%	0	-
1.5 Do you believe that information, in general, delivered in printed documents is easier to understand and carry out than those that are only spoken?	100%	10	0%	0	-
1.6 Would you add any other information pertinent to the managements to carry out the feeding that is not in this booklet? If so, which one?	50.00%	05	50.00%	05	-
1.7 Would you make this material available to palliative care clinic caregivers?	90.00%	09	10.00%	01	-
1.8 From 0 to 10, what grade do you assign to this booklet?	-	10	-	0	9.65

Table 2. Analysis of the data contained in the questionnaire applied to the caregivers/companions group

Survey Questions	Yes %	N	No %	N	Average Acceptance
2.1 After reading the booklet, were you able to understand the content covered therein?	100%	10	0%	0	-
2.2 Was the language used easy to understand?	100%	10	0%	0	-
2.3 Did you have difficulty understanding any information addressed in the booklet? If so, which one?	0%	0	100%	10	-
2.4 Do you think that information about the care contained in this booklet makes it easier to understand what to do about food?	100%	10	0%	0	-
2.5 Do you believe that the information delivered in this booklet was easier to understand and carry out than those that are only spoken?	100%	10	0%	0	-
2.6 Would you add any other information that you think should be in the booklet? If so, which one?	10.00%	01	90.00%	09	-
2.7 From 0 to 10, what grade do you assign to this booklet?	-	10	-	0	10.00

Chart 1. Assignments made by the caregivers/companions group

Attendee Assignment	Implementation
"[] I could have a better orientation for those who feed through the tube because I also find it dangerous even to guide about medications, those that can and those that cannot even because of not clogging. Also, emphasize on hygiene, especially those who use the tube both naso and gastro." (CA05)	It was not possible to add the suggested information as they are not part of the speech therapist's duties

Chart 2. Assignments made by the healthcare professionals group

Attendee Assignment	Implementation		
"Organize a sectorization in the booklet. One for general guidelines and one for patients with TQT" (PS01)	The applicability of sectorization in the booklet was conducted		
"It depends on the audience; if it is for the user, the language should be improved and the text reduced and the number of figures increased." (PS02)	The text underwent changes in the parts indicated by the researched public, as well as the addition of customized images to demonstrate the written guidelines		
"make it available online for dissemination." (PS03)	Online disclosure will be made		
"More Photos" (PSO4)	Developed new images to facilitate understanding		
"Black and white figures on positioning and use of simpler words and some excerpts." (PS10)	The addition of illustrative images and simplification of the text was conducted		

Caption: TQT = Tracheostomy.

The language used in information dissemination materials must include all audiences because, when associated with illustrative images, communication becomes effective, understanding of the exposed content is facilitated, and expanded knowledge promotes a dialogue between health professionals and users¹³.

It is even more relevant to ensure that there is an easily accessible language when it is observed that this research took place in the Northern Region of the country, where, according to the Brazilian Institute of Geography and Statistics (IBGE), there is an estimated illiteracy rate of 7.6% of the population, second only to the Northeast Region¹⁴.

Regarding the content in the booklet, both groups were asked if there was difficulty in understanding any item addressed, and 100% of the caregivers/companions group participants did not have difficulty with any of the items, as well as 80% of the health professionals. Only 20% of the group of health professionals pointed out doubts regarding the items "level of consciousness" and "comfort diet," whose participants PS09 and PS10 reported:

For us professionals, through practical and experiential expertise, we know how to safely identify states of consciousness; however, when we refer this information to family members, we perceive the emotional affections involved in having a sick family member without food, and not adequately discriminating states of alertness, the food administration in unsafe conditions. It is important to include in the booklet guidelines on states of consciousness and how to perceive them to favor family members' understanding in this regard... (PS10).

Item 9 (comfort diet), try to simplify a little more, maybe (PS09).

As highlighted by participant PS10, the perception of caregivers or companions of patients in palliative care can be affected throughout the illness of a loved one, as they participate in various aspects of the patient's life and face daily challenges, making it difficult to understand some commands passed on by the health team, and it is up to the professional to clarify, several times, if necessary, the information pertinent to the care¹⁵. In this case, pointing out a relevant item to add and improve the booklet since, with the material in hand, users can access this information when needed.

The item comfort diet or *Comfort Food*, as referenced by participant PS09, mentions the offer of food in order to assist in the comfort and emotional relief of the patient¹⁶. The comfort diet is a conduct of the speech therapist who works in palliative care. However, it is not a commonly found approach, which makes it necessary to explain its scope to caregivers, and a very simplified text can compromise the understanding of this practice. As mentioned, 100% of the participants in the group of caregivers/companions reported no difficulty understanding the content addressed in the booklet (Table 2, item 2.3).

Then, the questions asked in items 4 and 5 of both questionnaires ask whether the proposed booklet facilitated the understanding of the management necessary to carry out a safe diet and whether the guidelines contained therein are easier to follow and perform compared to information only passed on orally. Of the 20 participants, 100% agreed that the booklet facilitated the process of understanding the commands passed on.

The data obtained corroborate the findings in the literature that present the booklet as an educational technology to promote health education, facilitate the teaching-learning process of the population. Even with limitations, such as the level of education of the public



Figure 1. Booklet: "Care Guide for Safe Eating"

that receives the material, the booklets can disseminate information and favor assistance directed to the user¹⁷⁻¹⁹.

When asked if they would add any more pertinent information that was missing in the product that was delivered to them, 90% of the participants in the caregivers/companions group and 50% of the group of health professionals said they did not need to add any more information, while 10% and 50% of the respective groups said they wanted to add information.

The 10% increase in the caregivers/companions group refers to what was described by participant CA05, as shown in Table 1.

According to the Resolution of the Federal Council of Nutritionists (CFN) no. 600, of February 2018²⁰, it is the responsibility of the nutritionist to guide and supervise the administration, percentage of acceptance and tolerance of the oral and enteral diet; as well as, to the nurse, the administration; and, to the pharmacist,

the storage, acquisition and distribution of enteral diets, and guidelines on the use of medications via tube²⁰⁻²². The booklet delivered already has general guidelines on ideal posture to perform gavage and sanitation of alternative feeding routes.

Pertinent to the additions suggested by the group of health professionals (50% of the participants), the contributions set out in Chart 2 were observed, most of which reports refer to the use of a greater number of images, attribution made by 30% of the participants who contributed.

The use of images and illustrations in teaching materials such as the booklet facilitates the absorption of the knowledge being passed on, favors the understanding of the guidance provided to caregivers, and ensures the motivation to continue reading the material^{13,16}.

After the additions, the group of health professionals was asked if they would make the material available to caregivers of patients in palliative care admitted to the hospital where the research took place, in which 90% said they would share the material and 10% said they would not, using the justification: "It needs to be adapted to the language and level of education of patients and caregivers".

At the end, 20 participants assigned a score from zero to 10 to the booklet they received. Unanimously, participants in the group of caregivers/companions attributed a score of 10, as did 70% of the group of health professionals; 20% attributed a score of 9; and 10% attributed a score of 8.5. Results: The average approval of the booklet was 9.65 for the group of health professionals and 10.00 for caregivers/companions.

CONCLUSION

Educational booklets are excellent resources to promote health education, as they help in the understanding of guidelines passed on orally by the health team.

The speech therapy practice in palliative care is relatively recent, and presenting a material that guides caregivers and the health team itself on how to manage the diet of these patients and how to prevent risks related to bronchoaspiration is of great value to all involved.

The booklet entitled "Care Guide for Safe Eating" was highly approved by the researched public and was considered valid for use by caregivers or companions of patients in palliative care.

ACKNOWLEDGEMENTS

To all who contributed to the preparation of this article, especially to speech therapists Flávia Batista Monteiro and Douglas Rego Chaves.

CONTRIBUTIONS

Juliane Lisboa Pereira contributed substantially to the design and/or planning of the study; in the analysis and/or interpretation of the data; in the writing and/or critical review. Rosa de Fátima Marques Gonçalves contributed substantially to the analysis and/or interpretation of the data. Danielli Rodrigues da Silva Pinho contributed to the writing and/or critical review. All authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

FUNDING SOURCES

None.

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Recebido em 14/2/2023 Aprovado em 27/3/2023

Associate Editor: Livia Costa de Oliveira. Orcid iD: https://orcid.org/0000-0002-5052-1846 Scientific editor: Anke Bergmann. Orcid iD: https://orcid.org/0000-0002-1972-8777