



EDUCATIONAL BOOKLET FOR PATIENTS IN PALLIATIVE CARE AND THEIR FAMILIES: CONSTRUCTION STRATEGIES

CARTILHA EDUCATIVA PARA PACIENTES EM CUIDADOS PALIATIVOS E SEUS FAMILIARES: ESTRATÉGIAS DE CONSTRUÇÃO

CARTILLA EDUCATIVA PARA PACIENTES EN CUIDADOS PALIATIVOS Y SUS FAMILIARES: ESTRATEGIAS DE CONSTRUCCIÓN

Ana Inêz Severo Varela¹, Luciana Martins da Rosa², Vera Radünz³, Nádia Chiodelli Salum⁴, Ana Izabel Jatobá de Souza⁵

ABSTRACT

Objective: to elaborate an educational booklet for palliative care patients and their families. **Method:** this is a descriptive, qualitative study with 30 patients, 30 family members and 50 professionals assisted at the Center for Oncology Research. Data collection was held through semi-structured interviews and discussion groups. The results were submitted to the analysis technique of categorial content and the discussion groups were grouped by similarity. The contents of the booklet were structured based on the patients' needs, professional evaluation and narrative review. **Results:** the booklet was constructed containing the problems discussed with the study participants. The priority care was understanding of palliative care, feeding, autonomy, death and spirituality. **Conclusion:** the booklet is a nursing product for health education that can reduce uncertainties and help in home care. **Descriptors:** Health Education; Nursing; Technologies; Manuals; Palliative Care.

RESUMO

Objetivo: elaborar cartilha educativa para pacientes em cuidados paliativos e seus familiares. **Método:** estudo descritivo, de abordagem qualitativa, realizado com 30 pacientes, 30 familiares e 50 profissionais atendidos no Centro de Pesquisas Oncológicas. A coleta de dados por meio de entrevista semiestruturada e grupos de discussão. Os resultados foram submetidos à técnica análise de conteúdo na categorial e os do grupo de discussão foram agrupados por similaridade. Os conteúdos da cartilha foram estruturados a partir das necessidades dos pacientes, avaliação dos profissionais e revisão narrativa. **Resultados:** a cartilha foi construída contendo os cuidados problematizados com os participantes do estudo. Os cuidados prioritários foram: compreensão dos cuidados paliativos, alimentação, autonomia, morte e espiritualidade. **Conclusão:** a cartilha é um produto de enfermagem para educação em saúde que poderá reduzir incertezas e auxiliar nos cuidados domiciliares. **Descritores:** Cuidados Paliativos; Enfermagem; Tecnologia; Educação Em Saúde; Manual.

RESUMEN

Objetivo: elaborar cartilla educativa para pacientes en cuidados paliativos y sus familiares. **Método:** estudio descriptivo, de enfoque cualitativo, realizado con 30 pacientes, 30 familiares y 50 profesionales atendidos en el Centro de Investigaciones Oncológicas. La recolección de datos por medio de entrevista semiestructurada y grupos de discusión. Los resultados fueron sometidos a la técnica análisis de contenido categorial y los grupos de discusión fueron agrupados por similaridad. Los contenidos de la cartilla fueron estructurados a partir de las necesidades de los pacientes, evaluación de los profesionales y revisión narrativa. **Resultados:** la cartilla fue construida conteniendo los cuidados problematizados con los participantes del estudio. Los cuidados prioritarios fueron: comprensión de los cuidados paliativos, alimentación, autonomía, muerte y espiritualidad. **Conclusión:** la cartilla es un producto de enfermería para educación en salud que podrá reducir incertezas y auxiliar en los cuidados domiciliares. **Descriptores:** Educación en Salud; Enfermería; Tecnologías; Manuales; Cuidados Paliativos.

¹Nurse, Master's Degree in Nursing Care Management, Federal University of Santa Catarina. Florianópolis (SC), Brazil. E-mail: anainezmpenf@gmail.com; ²Nurse, Ph.D. Professor, Federal University of Santa Catarina. Florianópolis (SC), Brazil. E-mail: luciana.m.rosa@ufsc.br; ³Nurse, Ph.D. Professor, Federal University of Santa Catarina. Florianópolis (SC), Brazil. E-mail: radunz@ccs.ufsc.br; ⁴Nurse, Ph.D. Professor, Federal University of Santa Catarina. Florianópolis (SC), Brazil. E-mail: nchiodelli@gmail.com; ⁵Nurse, Ph.D. Professor, Federal University of Santa Catarina. Florianópolis (SC), Brazil. E-mail: aijsenf@gmail.com

INTRODUCTION

Information and communication technologies (ICT) have been used as a tool to provide, streamline and improve the process of health education for self-care and knowledge about the meaning of palliative care (PCs) or other health areas. For the multi-professional team working in the area of PCs for cancer patients, resources such as the creation of educational booklets bring more understandings and possibilities to assist in the daily construction of new knowledge among patients and their families.¹

The construction and development of educational booklets in the health education process favor a clear, simple and objective approach to information and guidance, including self-care practices. Thus, patients and families can understand the health-disease process and its relationship with the clinical condition experienced in the evolution of the disease, as well as the main needs of care, and also clarify doubts, reducing fears, anxieties and the unknown.²

Despite all technological resources and current knowledge, there is still a great deficit of knowledge and information by the patients in PCs, resulting from the difficulty of the approach of the professionals associated with the lack of training and of continuing education. Besides this reality, there are still social beliefs, which also influence professionals, patients and family members to link PCs to death.

For these reasons, it is essential to improve the professional qualification, but it is also essential that during the first careers in the oncological context in oncologic PCs, a greater approximation and creation of bonds that values the needs of the patients and their relatives, considering each meeting as an opportunity to enable them to understand PCs and to carry out care in the home environment that is manifested during the disease.³

In the PCs service of the Oncology Research Center (CEPON), it is observed in clinical practice the lack of knowledge about the meaning of PCs and the difficulty of following essential care at home. The professional guidelines are dialogued, but are not delivered in printed form, and are not available online on the institutional website. This condition reduces the learning required for daily care. Therefore, it is considered that the elaboration and availability of an educational booklet will be of great relevance for patients, their families and the multi-professional team.

In this context, it is questioned, how to construct an educational booklet in palliative care and what the contents and form of presentation are indicated by patients, relatives, professionals and scientific studies for its composition?

The elaboration of the educational booklet with the main orientations in PCs provides patients and families with better opportunities for adherence to the dialogues with the multi-professional team in the hospital context. Because reading the material after the dialogue with the professionals helps to review and assimilate the contents/guidelines, it allows a better understanding of the care that must be provided, reducing uncertainties and favoring quality of life, safety and health education. Health education through the provision of educational materials by the multi-professional team favors changes in health practices, aimed at improving the quality of services provided and increasing the understanding of patients and their families in the context of PCs.⁴

Thus, the objective of this study is to elaborate educational booklet for patients in palliative care and their relatives assisted at the Center for Oncology Research.

OBJECTIVE

- To elaborate educational booklet for patients in palliative care and their relatives.

METHOD

This is a descriptive study, with a qualitative approach. The setting of the study was the outpatient clinic and CPON hospitalization unit of CEPON, an oncology institution in the State of Santa Catarina (BR), a reference in PCs. The PCs service at CEPON was established in 1986, being the third service in Brazil to provide specialized assistance in PCs to the Brazilian population.⁵

The participants of the study were 30 patients and 30 family members assisted at the inpatient and outpatient unit at PCs and 50 professionals from the multi-professional team.

The inclusion criteria were patients hospitalized at the PCs unit, in rehospitalizations or hospitalized for at least three days or more at the first hospitalization (this time limit was established for an approximation with the team, the care routines, and the unit, allowing the patient to identify their information needs) that the accompanying family member agreed with their inclusion in the study; Patients assisted

at the PC clinic, with or without family follow-up; Familiar with the hospitalized patient and/or the patient in outpatient care; (A social worker, nine nurses, two pharmacists, nine physicians, two nutritionists, a psychologist, twenty four nursing technicians and one occupational therapist).

Exclusion criteria were patients with communication difficulties, under 18 years old, patients at the first outpatient visit, without previous hospitalization; Inpatients without family support; Patients attended at the outpatient clinic and in the hospitalization unit that had already been interviewed at the hospitalization unit and vice-versa; Professionals who are away from professional activities by license or vacation during the period of data collection.

For the construction of the booklet, some stages of development were followed:

1st stage: semi-structured interviews were conducted, containing open and closed questions with patients and their families. In this interview, the care that the participants indicated to make up the educational booklet on palliative care for CEPON and the understanding on palliative care were asked. Closed questions included the information patients indicated for insertion in the booklet, their doubts about PCs and about the PC unit, and the information they considered necessary for home care. The interviews were recorded by digital recorder and the reports were transcribed and submitted to content analysis.⁶

2nd stage: the first discussion group was held, when the results of the investigation with the patients and their relatives were presented to the professionals of the multi-professional team. This presentation took place in the case and study meeting, which occurs weekly in the study setting, in the meeting room of the hospitalization unit. After the presentation, the composition of the contents to be included in the booklet was discussed. The records of this activity were performed in field diary and the team recommendations were grouped by similarity.

3rd stage: the drafting of contents for composition of the booklet was elaborated. At this stage, the findings in the first and second stages guided the content definition, as well as the clinical experience of the principal investigator of this study in the context of the PCs. After this definition, a narrative review of the literature was developed, which included: textbook in PCPs⁷, manuals on CPs⁸⁻¹¹ and publications of the World Health Organization and the National Academy of Palliative Care.^{5,12} The findings were recorded

in a file grouped by similarity and adapted to common-sense language.

4th stage: the second discussion group was held, when the draft of the booklet (contents investigated and adapted for common sense) was presented for the evaluation of the multi-professional team. This moment was also used to define the layout of the booklet to guide the layout of the product. The records of this activity were performed in field diary and the recommendations were again grouped by similarity and later inserted in the booklet.

5th stage: the content of the booklet was evaluated by an expert nurse in PCs. This nurse is responsible for the division of PCs in the scenario of the study, a master in nursing, a specialist in oncology nursing and stomatotherapy and has been working in the PCs for 20 years. For this, the elaborated content (booklet) was given to the expert in printed form for detailed reading and contributions. The contributions were made on the material.

6th stage: the recommendations of the expert were included in the text and the layout was adjusted. In this stage, it was counted on the voluntary collaboration of plastic artist for the elaboration of the art (illustrative images) and of expert in editing and diagramming of texts.

7th stage: the final version of the booklet was presented to the multi-professional team for final evaluation and the printed booklet was made available, in print and digital, for the study scenario.

This study was approved by the Research Ethics Committee. The consolidated opinion is registered under the CAAE number 54588316.0.3001.5355. To keep the anonymity of the participants, the coding was used: letters PC (patient in palliative care) and FPC (family and patient in palliative care) followed by Arabic number in chronological order. The participants of the multi-professional team were not identified because the reports were recorded collectively. Thus, the dissemination of results obtained with professionals also occurred collectively.

RESULTS

The patients and families included in the study had a total of 60 participants: 15 patients and 15 family members assisted at the PCs inpatient unit, and 15 patients and 15 relatives assisted at CEPON's outpatient clinic. Among the participants, 18 (60%) were male. The ages ranged from 30 to 99 years old (mean of 64.73). Most participants were

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between 60 and 69 years old (30%) and 70 and 79 years old (26.67%).

The most frequent diagnoses of the types of neoplasias that affected the study participants were: prostate neoplasia (seven cases - 23.33%), lung or bronchial neoplasia (six cases - 20%), colon and rectum neoplasia (four cases - 13.33%) and neoplasia of the genital tract (four cases - 13, 33%).

The reports of the participants submitted to the content analysis resulted in the elaboration of three thematic categories:

Category: Understanding palliative care, CEPON and cancer control, including information on: health care provided by CEPON; Schedules and places of care, meaning and indication of palliative care and cancer control. The following are some testimonials to exemplify the category.

What each unit does here, because we have several questions, we ask and people speak different things, but I tell you that the people who work here are angels and very educated. (FPC3)

Nobody told me what palliative is, neither the doctor nor the nurses, only treat me very well, but I do not know what is the only thing down there that when we move to the second floor we will soon die. (PC6)

Category - Care for daily needs, including information about feeding, oral feeding and via nasogastric or nasoenteral tube, diabetes control and systemic arterial hypertension, body hygiene, autonomy in the activities and decisions, physical activities, eliminations of pain control; use of medications and their side effects. The following are some testimonials to exemplify the category.

Besides cancer he also has hypertension and diabetes, what do I do about food? (FPC6)

A way to facilitate understanding of the medications that can be taken together, beyond what is given here, because sometimes simple things happen at home and we do not have guidelines on how to act, only that we come to the emergency, but many times we do not have cars at the time and we can not come by bus. (PC10)

Category - Psycho-Psychiatric Care and Family Caregiver, covering information about spirituality, emotional security, spirituality, family support related to the dying process. Following are some testimonials to exemplify the category.

At home is very difficult, it is doubled care. At home, I do not have the doctor

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or the nursing team and then when I go home, there are people who know nothing and have no interest in learning, so how do I help to my family help me more, who helps me live far? (PC3)

Even though I know he has no cure, I believe in God and I have faith that he can be well. He (my father) has a lot of faith. (FPC3)

The evaluation of the multi-professional team in the second stage of construction of the booklet, based on patient and family reports, recommended that the booklet should include the following contents: a brief introduction presenting the booklet; meaning of palliative care and composition of the multi-professional team; description of health care offered by CEPON, hours and places of care; care with oral feeding and nasogastric or nasoenteral tube; brief explanations on the control of diabetes and systemic arterial hypertension; care with the use of medications and their side effects, with pain, bodily hygiene, autonomy, physiological eliminations, physical activities, death, spirituality, emotional security and family support.

The narrative review of the literature, sequentially, allowed the meeting of the contents needed to construct the text. The experience of the main researcher of this study in PCs favored the search, the adaptation of the language to the common sense and the definition of the titles of the contents.

The second evaluation of the multi-professional team and expert in PCs indicated adjustments in the writing of the text; adequacy of the language for PCs and the format of dialogue with patients and their families; reduction of technical terms; changes in the order of presentation of the contents.

As for the layout of the text, it was defined with the team the use of the Times New Roman, size 14 and use of the black color for the sources, light colors to highlight the presentation of the titles of the contents and the use of images that referred to the content addressed. The presentation of the contents totaled 19 pages. The final composition of the booklet with cover, back covers, preface, contents, references used, thanks, among others, totaled 40 pages.

The final titles of the contents of the educational booklet were introduction; CEPON, hours and places of care; palliative care; chemotherapy and radiotherapy; feeding

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care; care with nausea and vomiting; mouth care; care with constipation; care with diarrhea; care with shortness of breath; caring for physical, mental and emotional tiredness; care with body hygiene; care with autonomy; care of physical activities; care for pain; care with the use of medicines and their adverse effects; care for death; care with spirituality; caring for emotional security and support for family members.

Finally, there was the final evaluation of the team that approved the contents and layout and the availability of the booklet built for the study scenario. For this purpose, we opted for the delivery of a printed copy and in the digital format, for printed reproduction and for virtual availability in the institutional website.

DISCUSSION

The profile data reaffirm that cancer is a more common disease in advanced ages, consequently, PCs are manifested primarily in the elderly (60-74 years old). The results of this study resemble another study carried out in the State of Minas Gerais, which evaluated the profile of patients with indication of palliative care. It pointed out the male prevalence (60.5%), the mean age of the patients of 62 years old, and the maximum age of 100 years old. What differentiated it was the minimum age that was 20 years old,¹³ that is, ten years less than in this study. This difference is related to the research scenario. In Minas Gerais study, the research was performed in a medical clinic unit and in the scenario of this study in a unit specialized in PCs.

Regarding the diagnosis of patients, the findings of this study differ from another study, which analyzed the demand of patients in PCs according to the type of cancer in the State of Rio de Janeiro. The findings showed the predominance of onco-hematological diseases,¹⁴ while solid tumors prevailed in this study. In international estimation, solid tumors are equivalent to 93.9% of the cases, while onco-hematologic accounts for 6.1% of cancer cases, excluding non-melanoma skin cancers.¹⁵ Thus, this study shows the incidence of most the populations.

Regarding the results obtained in the thematic categories, it is worth noting that despite scientific, technological and media development, patients still claim information, health education and the care associated with everyday life, psychosocial, emotional, including spirituality. Faced with cancer and the impossibility of healing, but in the face of the need for daily care, these aspects take on

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more force, and the role of the team, as educating professionals, becomes essential.

Communication, information and health education are basic pillars in PCs. The training of professionals for good communication is unique competence in the context of PCs, needing to be continued and not exclusive in times of interurrences or aggravations, or even in terminality.¹⁶

Another point that stands out is the lack of knowledge about the real meaning of PCs, because unfortunately the PCs' relationship with early death and an uncertain future continues, causing fears, discomforts and doubts about the path and choices that must be made.

A study carried out in the State of São Paulo reports that the indication for PCs occurs when the disease is very advanced, contributing to the social representation that PCs are related to death, and also, hindering and accepting the patients and their relatives being cared by the philosophy of PCs, because they believe that this service is only provided at the end of life.¹⁷

The method adopted for the construction of the educational booklet in PCs, problematizing the practice together with the patients and their families, provided a new look at self-care education in the study setting. Also, it assisted in the rapprochement and creation of new ties with patients and their families.

The inclusion of the multi-professional team was of great importance for the development of the educational booklet, since in the process of constructing educational materials the sum of the experiences and the creativity allows the creation of materials with better contents and better forms of presentation, facilitating the dialogue even to the distance with patients and their families.

In the problematization, there is the valorization and the sum of the different looks that compose the team, working in this way, with a single objective focused on the quality of life in the health-disease process.¹⁸

It is emphasized that, the scenario team in this study has a habit of discussing clinical cases and multi-professional clinical visits. This work strategy favored the problematization and construction of the booklet.

Developing strategies for improvement in care practice, such as the development of educational materials based on research and scientific studies, combine theory with practice and allow changing the reality of care. The problematization of practice allows

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that proposed changes can be accepted and carried out by health professionals as an indispensable practice in everyday life, linking the philosophy of PCs based on health care aimed at quality of life and humanization.¹⁹

The quality of life of the patients in PCs and their relatives changes significantly. Health education can alleviate the uncertainties and fears that the illness process brings. The educational booklet constructed through this study has this purpose.

The production of educational booklets plays an important role in the development of skills and autonomy in the activities and decisions of patients and their families,¹⁸ reaffirming the relevance of the object of this study.

Health education carried out through educational guides, a health technology, favors a better quality of life, more safety in the care process, and guidelines pertinent to patients and their families.

The development of strategies for improving care practices, as well as the development of educational materials through language and a clear approach, are important tools that contribute to the communication process with patients and their families, making them more active in their self-care and improving the understanding of the clinical condition in which the patient is found.²⁰

This study had the collaboration of specialized professionals for illustration and elaboration of the booklet layout (editing and diagramming of the nursing product). This possibility was perceived as contributing to facilitate the reading of the text, the comprehension of the contents and the attractiveness of the text. The inclusion of specialists, both in the content definition stage (professionals of the multi-professional team and expert in PCs), and in the illustration and diagramming phase was essential, since the product combined content, beauty and attractiveness. It is considered that these characteristics favor health education, in this case, for the self-care of patients in palliative condition of life and their relatives.

Self-care is understood as the practice of actions that individuals initiate and execute on their own to maintain life, health, and well-being. It consists of the care taken by the person himself for himself. It is built with the diverse experiences of life and the state of maturity of each person. However, at the onset of the life trajectory, the deficit of self-care may occur, when then, there is a need

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for health education for new learning, and there may be a need for the care of relatives (or other caregivers) and nursing care and other health professionals to meet the needs of care and new knowledge.²¹

The illustration for the presentation of the educational material contributes to the orientation and emphasis of main points and ideas, becoming an important resource to answer the questions in a simple way, allowing the patients in PCs and their relatives to identify with the content both in the hospital as the home environment.²²

The production of the educational booklet by this study configured a health product to facilitate the confrontation of the diagnosis of cancer and the palliative condition. Health products are tools that favor care, which can reduce discomforts, lack of knowledge and comfort to life, qualify care and improve the results achieved, and give greater visibility to the profession, Nursing in this case.

The use of educational technologies enables a higher quality of teaching-learning and communication in health care, intensifying the guidelines passed by the professional to the patient and their families. This study shows the efficiency of the use of the educational booklet, affirming that this type of instrument is capable of promoting positive changes for the acquisition of knowledge, helping in the process of adaptation to the incurable chronic disease.²³

Therefore, the use of educational guides as a support for communication does not replace professional, patient and family communication, but it is extremely important to help and facilitate that the guidelines are understood as soon as possible, contributing to education in health, empowering for self-care and strengthening the maintenance of good practices in the daily life of PCs.²⁴

Another study says that the construction of technology and communication products aimed at health education activities, in the desire to encourage patients and their families to maintain good practices in PCs, should be used by all members of the multi-professional team to better quality of life in a significant way and, if used, the production of other educational technologies. Associating technology and education in health is a need verbalized by professionals, patients and family caregivers.²⁵⁻⁷

As limit of this study, the non-validation of the booklet with the patients and relatives after the end of its production is registered.

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Corresponding Address

Ana Inês Severo Varela
Condomínio Residencial Avenida das Torres
Bom Pastor, 1457
Bairro Barreiros
CEP: 88111-152 – São José (SC), Brazil