

Scientific production about palliative care and communication in online journals: a scoping review

Produção científica acerca dos cuidados paliativos e comunicação em periódicos online: revisão de escopo Producción científica acerca de los cuidados paliativos y comunicación en periódicos online: revisión de escopo

> Cristiani Garrido de Andrade¹ ORCID: 0000-0002-9386-0549

ORCID: 0000-0002-2611-8643

Maria Eliane Moreira Freire^I ORCID: 0000-0002-0305-4843

Thaina Karoline Costa Dias^I ORCID: 0000-0002-7265-1350

Jael Rúbia Figueiredo de Sá França¹ ORCID: 0000-0002-9968-5366

Solange Fátima Geraldo da Costa¹ ORCID: 0000-0002-6555-8625

'Universidade Federal da Paraíba. João Pessoa, Paraíba, Brazil. "Universidade Federal de Alfenas. Alfenas, Minas Gerais, Brazil.

How to cite this article:

Andrade CG, Costa ICP, Freire MEM, Dias TKC, França JRFS, Costa SFG. Scientific production about palliative care and communication in online journals: a scoping review.

Rev Bras Enferm. 2021;74(2):e20190378.

https://doi.org/10.1590/0034-7167-2019-0378

Corresponding author:

Cristiani Garrido de Andrade E-mail: cristiani_garrido@hotmail.com

EDITOR IN CHIEF: Antonio José de Almeida Filho ASSOCIATE EDITOR: Rafael Silva

Submission: 08-14-2019 **Approval:** 02-25-2020

ABSTRACT

Objectives: to characterize publications about palliative care and communication, with an emphasis on the approaches addressed, disseminated in online journals. **Methods:** it is a scope review, in which the mnemonic strategy Problem, Concept and Context was used, based on database research. The sample consisted of 86 publications. **Results:** most publications were written in the English language, published in the journal BMC Palliative Care, and with level of evidence IV. As for the approaches approached, the following stand out: Importance of communication in palliative care; Preaking the bad news in palliative care; Training professionals/staff to communicate in palliative care; and Communication strategies in palliative care. **Final Considerations:** the review made it possible to map a significant number of publications on palliative care and communication. It is recommended to produce new studies with better scientific evidence that guide the assistance of health professionals. **Descriptors:** Palliative Care; Communication; Hospice Care; Nursing; Scientific.

RESUMO

Objetivos: caracterizar as publicações acerca dos cuidados paliativos e comunicação, com ênfase nos enfoques abordados, disseminadas em periódicos online. Métodos: trata-se de uma revisão de escopo, em que se utilizou a estratégia mnemônica Problema, Conceito e Contexto, com base na pesquisa em bases de dados. A amostra foi constituída de 86 publicações. Resultados: a maioria das publicações foi escrita no idioma inglês, publicadas no periódico BMC Palliative Care, e com o nível IV de evidência. Quanto aos enfoques abordados, destacam-se: Importância da comunicação em cuidados paliativos; Comunicação de más notícias em cuidados paliativos; Capacitação de profissionais/equipe para a comunicação em cuidados paliativos; e Estratégias de comunicação em cuidados paliativos. Considerações Finais: a revisão possibilitou mapear um quantitativo expressivo de publicações sobre os cuidados paliativos e comunicação. Recomenda-se a produção de novos estudos com melhor evidência científica que direcionem a assistência dos profissionais de saúde.

Descritores: Cuidados Paliativos; Comunicação; Cuidados Paliativos na Terminalidade da Vida; Enfermagem; Científica.

RESUMEN

Objetivos: caracterizar publicaciones sobre cuidados paliativos y comunicación, con énfasis en los enfoques cubiertos, difundidos en revistas *online*. **Métodos:** esta es una revisión del alcance, en la que se utilizó la estrategia mnemónica Problema, Concepto y Contexto, basada en la investigación de bases de datos. La muestra consistió en 86 publicaciones. **Resultados:** la mayoría de las publicaciones fueron escritas en inglés, publicadas en la revista BMC *Palliative Care* y con evidencia de nivel IV. En cuanto a los enfoques abordados, destacan los siguientes: importancia de la comunicación en los cuidados paliativos; Comunicación de malas noticias en cuidados paliativos; Capacitación de profesionales/personal para comunicarse en cuidados paliativos; y estrategias de comunicación en cuidados paliativos. **Consideraciones Finales:** la revisión permitió mapear un número significativo de publicaciones sobre cuidados paliativos y comunicación. Se recomienda realizar nuevos estudios con mejor evidencia científica que guíen la asistencia de los profesionales de la salud.

Descriptores: Cuidados Paliativos; Comunicación; Cuidados Paliativos al Final de la Vida; Enfermería; Científica.



INTRODUCTION

Knowledge in the area of palliative care has evolved exponentially, which may be linked not only to the advancement of Science, but also to the search for a more individualized view of the patient, in addition to his/her illness, considering all its complexity⁽¹⁾. In this context, palliative care emerges as a caring approach, which integrates physical, psychological, social and spiritual aspects in patient and family care.

Palliative care was redefined by the World Health Organization (WHO) in 2002, as a care approach, promoted by a multidisciplinary team. Palliative care aims to improve the quality of life of patients and their families, who face problems associated with diseases chronic, progressive and incurable, from early identification, correct assessment and treatment of pain, and other physical, psychosocial and spiritual problems⁽²⁾.

Controlling the symptoms that distress the patient, psychosocial and spiritual assistance and attention to family members, are the fundamental principles of palliative care, which go back to a type of care aimed at patients from the diagnosis of a progressive, advanced and incurable disease to the family's mourning process⁽³⁾.

This care is supported by a relational process between the professional, the patient and the family, in order to minimize the problem of diagnosis and prognosis of the disease. For this reason, the assistance of the team to patients undergoing palliative care and their families requires professionals to use individualized care⁽⁴⁻⁵⁾, who give positive responses, according to the need, conditions and the adherence of each person. In this sense, in order to establish the relational process, it is imperative that professionals use communication.

A study points out that communication is the fundamental basis, through which interpersonal relationships are established, a therapeutic aid instrument that anchors the provision of individualized care that the patient in palliative care needs⁽⁶⁾. In the scope of health care, communication is a vital, inherent and necessary component and involves not only the care of professionals and patients, but also the relationship between professionals, patients and their families, among other areas, with the purpose to promote humanized care⁽⁷⁾.

Despite the importance of communication in the field of palliative care, the need to develop studies that seek to mediate human relationships, promote bonding and the consolidation of autonomy is justified, given the individual perspectives of patients in palliative care and their families. In view of the above, considering communication as a diagnostic and therapeutic element, capable of identifying care demands and receiving patients and family members therapeutically, the aim was to develop this study and spreading scientific production in the national and international scenario to from publications disseminated in online journals.

OBJECTIVES

To characterize publications about palliative care and communication, with an emphasis on the approaches addressed, disseminated in online journals.

METHODS

This is a scope review or scoping study. This type of investigation aims to map the fundamental concepts that underpin a given theme, to verify the expansion, scope and nature of existing research. For that, it uses a systematic review, which aims at narrative synthesis⁽⁸⁾. It is noteworthy that this type of research has been growing in the area of health, especially in nursing. In this sense, the following publications deserve special mention: Nursing Care in Healthcare-Associated Infections: A Scoping Review⁽⁹⁾; Community interventions related to intimate partner violence among adolescents: scope review⁽¹⁰⁾; Health professionals' practices related with tourniquet use during peripheral venipuncture: a scoping review⁽¹¹⁾; Nursing Interventions in the Enhanced Recovery After Surgery*: Scoping Review⁽¹²⁾; and The scenario of scientific publication on palliative care in oncology over the last 5 years: a scoping review⁽¹³⁾.

Therefore, it is undeniable the contribution of studies in the scope review to map relevant and current research, since it will contribute to subsidize professionals in their practice and researchers to produce new research on the topic.

In order to achieve the proposed objective, the six methodological steps recommended by this modality were identifying the research question; searching for relevant studies; selecting the studies, with two researchers working independently; extracting data; separating, summarizing and reporting results; and disseminating results^(8,14).

In order to carry out the steps of the proposed research, the PCC mnemonic strategy - Problem (which one intends to investigate), Concept (basic concept to be examined in the review) was used; and Context (specific aspects about a given theme, being consistent with the object of study)⁽¹⁵⁾. The best way to reach an effective question that directs the review work is using the aforementioned strategy⁽¹⁵⁾. Thus, this strategy was used in order to guide the question formulation and construction of criteria for the bibliographic search, so that the researcher would effectively locate the best scientific information available, through the identification of these key topics.

In the proposed study, the *problem* listed was the characterization of scientific publications about palliative care and communication, with an emphasis on the approaches addressed, disseminated in online journals; the *concept* encompassed palliative care and communication; and the *context* involves the number of studies, the databases in which they were published, the language, the frequency of publications in the last five years, to professional area of the authors, the level of evidence of the studies, as classification system⁽¹⁶⁾, and the most researched topics.

Thus, the research question was obtained: What is the characterization of publications about palliative care and communication, with an emphasis on the approaches addressed, disseminated in online journals from 2014 to 2018?

Once the research question was defined, the literary corpus to be analyzed was surveyed, following the PCC strategy, through the following descriptors: 'Cuidados Paliativos'; 'Palliative Care'; 'Comunicação'; 'Communication' and 'Comunicación'. In order to cross the descriptors, the Boolean operator AND was used. The first search was carried out in the Latin American & Caribbean Health Sciences Information (LILACS) database, in the Brazilian

Nursing Database – BDENF (Base de Dados Brasileira de Enfermagem) - and in the Index Psi - Technical-scientific journals. In the second search, Medical Literature Analysis and Retrieval System Online/Pubmed (MEDLINE) was used.

To select publications, the following inclusion criteria were used: scientific articles published in English, Portuguese or Spanish, from January 2014 to December 2018, whose titles included the terms 'palliative care' and 'communication' and that were available in full for access online. Studies that did not address aspects related to the topic were excluded, as well as repeated studies. The searches were carried out in January 2019.

The study inclusion process was systematized using the PRISMA methodology (Preferred Reporting Items for Systematic Reviews and Meta-Analyzes)⁽¹⁷⁾. Thus, articles' titles and abstracts found in the search were read and analyzed by one of the authors in order to elect those who would be part of the research. In situations of doubt, the articles went on to the next phase, which involved the complete reading of each of the articles selected by two independent authors, in order to confirm the relevance of the review question and, if so, to extract the data of interest. Then, at a later stage, the results were checked and disagreements were resolved by consensus between the two researchers. Thus, the sample consisted of 86 publications.

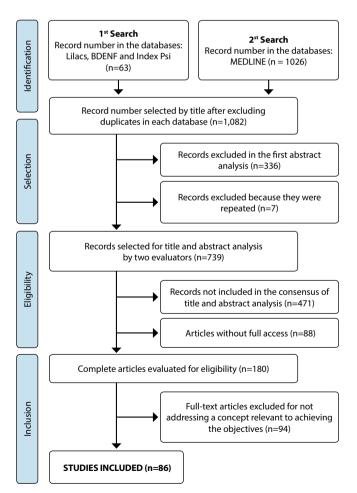


Figure 1 - Process of identification and inclusion of studies - Preferred Reporting Items for Systematic Reviews and Meta-Analyzes (PRISMA) diagram flow, João Pessoa, Paraíba, Brazil

It is important to note that scope reviews do not ensure the exclusion of articles according to methodological quality criteria, as they are more inclusive and allow researchers to identify gaps in the investigation⁽¹³⁾.

Figure 1 explains the results of each step of the analysis, according to the model PRISMA 2009 Flow Diagram⁽¹⁷⁾.

For the stage of separation, summarization and report of the essential information of each study, a structured instrument was elaborated, in order to make it possible to record the data of the publications included in the study. This stage contained article title, data base, language, journal (title), level of evidence, profession of the authors, set of authors (uniprofessional - articles with authors from only one professional or multidisciplinary category - articles with authors from two or more professional categories), method, abstract, and conclusion. This instrument enabled the synthesis, interpretation of data and basic numerical analysis of the distribution of studies included in the review.

In the final step, the results were compiled and communicated, with the aim of presenting an overview of all the material, with the elucidation of main approaches for analysis, through which it was possible to synthesize the findings in a narrative way.

RESULTS

In the first search strategy, 63 studies were identified; and in the second, 1,026. Screening covered the stages of analysis by titles and by abstract. Based on title, 336 articles were excluded, and seven were also repeated because they were repeated in more than one database, with 739 abstracts remaining to be analyzed by two reviewers. Through the consensus, 471 studies were excluded and, 88, as they were not available in full. Therefore, 86 studies were part of this review, considering that 94 were eliminated because they did not address a relevant concept for achieving the objectives.

Among 86 (100%) publications found, 39 (45.3%) were selected in the LILACS database, and 47 (54.7%) in MEDLINE. Of the seven publications repeated in more than one database, five were in LICACS and BDenf and two in LILACS and Index Psi.

Regarding the language in which the articles were written, 48 (55.8%) were published in English, 36 (41.9%) in Portuguese, and two (2.3%) in Spanish. As for the year of publication, it was observed that the highest frequency of publications occurred in 2017, with 27 (31.4%) productions. In 2018, 2016, 2015 and 2014 and, 18 (21.0%), 11 (12.7%), 16 (18.6%) and 14 (16.3%) studies were published, respectively.

The amount of annual and cumulative production over the past five years is shown in Figure 2, below.

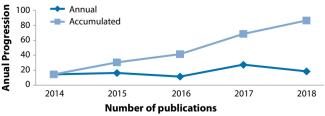


Figure 2 - Distribution of scientific production on communication in palliative care, published *online* in the period from 2014 to 2018, João Pessoa, Paraíba, Brazil, 2019, (n=86)

As for publication journals, important journals stood out, with emphasis on BMC Palliative Care, *Revista Bioética*, Palliative & Supportive Care and Journal of Pain and Symptom Management, represented, respectively, by seven (8.1%), six (6.9%), five (5.8%) and five (5.8%) of the publications included in this review.

Regarding the level and quality of evidence of the articles, it was found that most studies are classified as level IV, with a total of 40 (46%) articles, level VI, with 19 (22%) productions, and level III, with 17 (20%) studies. Level I was observed in six (7%) studies, and level II in four (5%). Level V was not applied in the search articles (Table 1).

Table 1 - Distribution of publications according to the level and quality of evidence, following the classification system proposed by Stetler et al (1998), João Pessoa, Paraíba, Brazil, 2019, (n=86)

Level and quality of evidence	Sources of Evidence	n	%
1. LEVEL I	Meta-analysis of multiple controlled studies	06	07
2. LEVEL II	Individual randomized controlled experimental study	04	05
3. LEVEL III	Quasi-experimental study as a single group, non-randomized, controlled, with pre and post test, or paired case-control studies	17	20
4. LEVEL IV	Non-experimental study as descriptive correlational research, qualitative research or case study	40	46
5. LEVEL V	Report of cases or data obtained systematically, of verifiable quality, or data from evaluation programs	00	00
6. LEVEL VI	Opinion from respected authorities (such as nationally known authors) based on their clinical experience or the opinion of a committee of experts including their interpretations of information not based on research. Includes opinions from regulatory or legal bodies.	19	22
Total		86	100

With regard to the professional category of the authors of the analyzed productions, the research indicated that 40 (46.5%) studies were published by nurses; 36 (41.9%), by doctors, who participated as authors; seven (8.1%), by psychologists; two (2.3%), by speech therapists; and one (1.1%), for occupational therapists, social workers and physical therapists. It was possible to identify publications with the authorship of more than one professional category.

In the group of authors, the form of uniprofessional production is present in 66 (76.7%) of the studies that comprised the sample, and the multidisciplinary form in 20 (23.3%) of the publications. When relating the professional category to the form of production, the result is that doctors produced 30 (34.9%) of the total articles published in a multidisciplinary way, and 27 (31.4%), in a uniprofessional way. Nurses, on the other hand, participated in 17 (19.8%) productions in a multidisciplinary way, and 39 (45.3%), uniprofessional authorship. The production by professional category and the uni and multidisciplinary form are described in Figure 3.

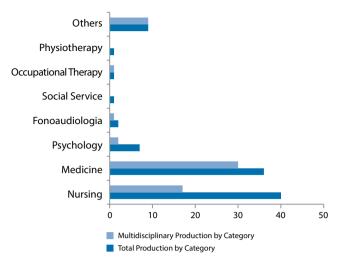


Figure 3 - Distribution of the scientific publication on communication in palliative care, according to the frequency of each professional category related to the form of production, João Pessoa, Paraíba, 2019, (n=86)

When analyzing the full texts of the 86 selected articles, the thematic approaches of interest for each publication were identified, organized in Chart 1.

Chart 1 - Approaches addressed in publications about palliative care and communication, João Pessoa, Paraíba, Brazil, 2019, (n=86)

FOCUS IMPORTANCE OF COMMUNICATION IN PALLIATIVE CARE. n=29 (33.7%)

A1 The communication experiences of patients with palliative care needs: a systematic review and meta-synthesis of qualitative findings.

(Palliat Support Care)

A2 Palliative nursing care in the elderly in UCI: an integrative review. (Rev. Pesqui. -Univ. Fed. Estado Rio L. Online)

A3 Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators. (J Pain Symptom Manage)

A4"Save the Elderly!": Care Report in Health Psychology and Palliative Care. (Psicol. ciênc. prof.)

A5 Validation of a model of family caregiver communication types and related caregiver outcomes. (Palliat Support Care)

A6 Family communication and decision making at the end of life: a literature review. (Palliat Support Care)

A7 Palliative Care and Curriculum Guidelines: Necessary Inclusion. (Rev. bras. educ. méd.)

A8 Barriers associated with palliative care in dementia: a review of the literature. (Geriatr., Gerontol, Aging)

A9 Main Caregivers Facing Death Experience and Its Meanings. (Psicol. ciênc. prof.)

A10 Clinical and laboratory characteristics associated with referral of hospitalized elderly to palliative care. (Einstein - São Paulo)

A11 Nursing and spiritual needs in the terminal patient. (Enfermería: Cuidados Humanizados)

A12 Patient's rights to advance directives. (Rev. bioét.)

A13 The importance of communication in sustaining hope at the end of life. (Br J Nurs.)

A14 From one side to the other: what is essential? Perception of oncology patients and their caregivers in the beginning of oncology treatment and in palliative care. (Einstein - São Paulo)

A15 Palliative care to the elderly in intensive care: the perspective of the nursing team. (Texto & contexto enferm.)

A16 Design of, and enrollment in, the palliative care communication research initiative: a direct-observation cohort study. (BMC Palliat Care)
A17 Communication during palliative care and end of life: perceptions of experienced pediatric oncology nurses. (Cancer Nurs.)

A18 Meaning of palliative care by the multiprofessional team of the intensive care unit. (Rev enferm UFPE on line.)

To be continued

Chart 1

A19 Palliative care: nurses vision of a teaching hospital. (Enferm. Foco) **A20** The importance of palliative care provided by the nurse for children with cancer in terminal phase. (Rev. Pesqui. -Univ. Fed. Estado Rio J., Online)

A21 Care to terminal patients. Perception of nurses from the intensive care unit of a hospital. (Invest. educ. enferm.)

A22 Palliative care in primary health care: ethical considerations. (Rev. bioét.)

A23 Nursing professional communication with the family of the terminal patient. (Enferm. univ.)

A24 Patterns of interactions among patients with advanced pancreatic cancer, their caregivers, and healthcare providers during symptom discussions. (Support Care Cancer)

A25 A longitudinal communication approach in advanced lung cancer: A qualitative study of patients', relatives' and staff's perspectives. (Eur J Cancer Care).

A26 Communication and quality of care on palliative care units: a qualitative study. (J Palliat Med.)

A27 Communication and swallowing difficulties in palliative patients: patients, families and/or caregivers perspective. (Audiol., Commun. res.) **A28** Palliative care seen from the point of view of the lung cancer patients' families. (Interface - Botucatu, Online)

A29 Proposal of Speech-Language Pathology activities in Palliative Care in hospitalized oncology patients. (Distúrb Comun.)

FOCUS

BREAKING THE BAD NEWS IN PALLIATIVE CARE. n=26 (30.2%)

B1 'I can't tell my child they are dying'. Helping parents have conversations with their child. (Education and Practice)

B2 Declining oral intake towards the end of life: how to talk about it? A qualitative study. (Int J Palliat Nurs.)

B3 Mismatch between physicians and family members views on communications about patients with chronic incurable diseases receiving care in critical and intensive care settings in Georgia: a quantitative observational survey. (BMC Palliat Care)

B4 Patients' preferences for information about the benefits and risks of second-line palliative chemotherapy and their oncologist's awareness of these preferences. (J Cancer Educ.)

B5 Breaking bad news about transitions to dying: a qualitative exploration of the role of the District Nurse. (Palliat Med.)

B6 Communication about the impending death of patients with cancer to the family: a nationwide survey. (BMJ Support Palliat Care)

B7 Discussing serious news: teaching communication skills through role play with bereaved parents. (Am. j. hosp. palliat. care.)

B8 How long do I have? Observational study on communication about life expectancy with advanced cancer patients. (Patient Educ Couns)

B9 ICU bedside nurses' involvement in palliative care communication: a multicenter survey. (J Pain Symptom Manage)

B10 Reframing the goals of care conversation: "we're in a different place". (J Palliat Med.)

B11 Children and adolescents with cancer under palliative care: experience of family members. (REBEn)

B12 Communicating bad news: an integrative review of the nursing literature. (REBEn)

B13 End-of-Life Paradigm in Medical Training: Attitudes and Knowledge about Death and Palliative Care. (Rev. bras. educ. méd.)

B14 Interpersonal communication with oncological patients in palliative. (Rev baiana enferm.)

B15 Clinical and laboratory characteristics associated with referral of hospitalized elderly to palliative care. (Einstein - São Paulo)

B16 Palliative care consultation in an intensive care unit. (Arq. Catarin Med.)

B17 Ethical problems identified by nurses in relation to patients in critical condition. (Rev. bioét.)

B18 The doctor-family relation when facing terminality in ICU. (Psicol. argum.)

B19 Optimistic perspectives in communicating difficult news on fetal development. (Cad. saúde pública)

B20 A systematic review of end-of-life care communication skills training for generalist palliative care providers; research quality and reporting guidance. (J Pain Symptom Manage)

B21 The doctor-patient relationship and information-seeking behavior: four orientations to cancer communication. (J Palliat Care)

Chart 1

B22 Communication behaviors and patient and caregiver emotional concerns: a description of home hospice communication. (Oncol Nurs Forum)

B23 Communication in heart failure and palliative care. (Heart Fail Rev.)

B24 Communicating reserved prognosis to child patients. (Rev. bioét.)

B25 Nursing support of home hospice caregivers on the day of cancer patient death. (Oncol Nurs Forum.)

B26 Social representation of nurses on palliative care. (Rev. cuid.)

FOCUS

TRAINING PROFESSIONALS/STAFF FOR COMMUNICATION IN PALLIATIVE CARE. n=16 (18.6%)

C1 Communication in palliative care: the applicability of the SAGE and THYME model in Singapore. (Int J Palliat Nurs.)

C2 The entry-level physical therapist: a case for comfort communication training. (Health Commun.)

C3 Self-assessment scores improve after simulation-based palliative care communication skill workshops. (Am J Hosp Palliat Care.)

C4 Are future medical oncologists sufficiently trained to communicate about palliative care? The medical oncology curriculum in Flanders, Belgium. (Acta Clin Belg.)

C5 Palliative care communication in the icu: implications for an oncology-critical care nursing partnership. (Semin Oncol Nurs.)

C6 The effect of communication skills training for generalist palliative care providers on patient-reported outcomes and clinician behaviors: a systematic review and meta-analysis. (J Pain Symptom Manage)

C7 Assessment of an interprofessional online curriculum for palliative care communication training. (J Palliat Med.)

C8 Challenges to the Integrality of Assistance in Palliative Care in the Pediatric Ward of the National Cancer Institute José Alencar Gomes da Silva. (Rev. bras. cancerol.)

C9 'Difficult Conversations': evaluation of multiprofessional training. (BMJ Support Palliat Care)

C10 The effectiveness of communication-skills training interventions in end-of-life noncancer care in acute hospital-based services: A systematic review. (Palliat Support Care)

C11 Palliative Care: Importance of the Subject for Medical Students. (Rev. bras. educ. méd.)

C12 Educational intervention in the nursing team beyond palliative care. (J. Health Biol. Sci.)

C13 Barriers and facilitators to end-of-life communication in advanced chronic organ failure. (Int J Palliat Nurs.)

C14 The effectiveness of the Geritalk communication skills course: a real-time assessment of skill acquisition and deliberate practice. (J Pain Symptom Manage)

C15 The use of simulation to teach nursing students and clinicians palliative care and end-of-life communication: a systematic review. (Am J Hosp Palliat Care)

C16 Improving communication with palliative care cancer patients at home - A pilot study of SAGE & THYME communication skills model. (Eur J Oncol Nurs.)

FOCUS

COMMUNICATION STRATEGIES IN PALLIATIVE CARE. n=15 (17.4%)

D1 Striving for a balance between leading and following the patient and family - nurses' strategies to facilitate the transition from life-prolonging care to palliative care: an interview study. (BMC Palliat Care)

D2 What is the evidence for conducting palliative care family meetings? A systematic review. (Palliat Med.)

D3 Keep in Touch (KIT): feasibility of using internet-based communication and information technology in palliative care. (BMC Palliative Care)

D4 The grim reaper, hounds of hell, and dr. death: the role of storytelling for palliative care in competing medical meaning systems. (Health Commun)

D5 Keep in touch (KIT): perspectives on introducing internet-based communication and information technologies in palliative care. (BMC Palliat Care)

D6 Communication about existential issues with patients close to death--nurses' reflections on content, process and meaning. (Psychooncology)

To be continued

To be continued

Chart 1 (concluded)

D7 A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. (Psychooncology)

D8 Talking about sensitive topics during the advance care planning discussion: a peek into the black box. (Palliat Support Care)

D9 The troubles of telling: managing communication about the end of life. (Qual Health Res.)

D10 A comprehensive review on palliative care. (Acta Medica)

D11 Palliative care and communication: study with health professionals of the home care service. (Rev. Pesqui. -Univ. Fed. Estado Rio J., Online)

D12 Use of communication strategies in palliative care in brazil: Integrative review. (Cogitare Enferm.)

D13 Communication in the transition to palliative care: review article. (Rev. bras. educ. méd.)

D14 Ethical issues related to patient preferences in palliative care. (Rev. bioét.)

D15 Communication in palliative care: an integrative literature review. (Rev. bras. ciênc. saúde.)

The results of this scope review pointed to a prevalence of publications in the English language, in relation to the Portuguese and Spanish languages. Such evidence may be linked to the fact that countries that develop palliative care in a more advanced way are concentrated in North America and Europe and because research in this area is mostly planned and developed in English-speaking countries⁽¹⁸⁾.

It should also be noted that there is a worldwide trend to establish English as the international language of Sciences, because the publication of studies in a language understood by most individuals increases the likelihood of being cited later and of researchers from all over the world. communicate and share knowledge⁽¹⁹⁾.

Regarding the level and quality of the evidence of the articles, it was found that most studies are classified as level IV, which is related to non-experimental studies, such as correlational descriptive research, qualitative research or case study⁽¹⁶⁾. As can be confirmed in this research, it is necessary to develop studies that have a higher level of scientific evidence in the area of palliative care and communication, so that they can be applied in patient care. This fact may be related to the subjectivity present in the theme and due to biomedical thinking.

A review study on palliative care also demonstrated the discreet presence of levels of evidence in publications, due to the greater number of exploratory, descriptive, qualitative studies developed with small sample sizes, consisting of cancer patients and service professionals⁽²⁰⁾. Mapping points out that the professional fields of nursing and medicine are the ones that most produce scientific articles on palliative care and communication. This corroborates the outcome of other studies that research on the referred subject^(12,21-22).

As the study points out, the professional category that most publishes about palliative care is that of nurses, because the very essence of their education is based on care⁽²³⁾. However, in palliative care, communication skills must be performed by an interdisciplinary team, with emphasis on doctors, nurses and psychologists. A study⁽²¹⁾ highlights that the growing interest of these professionals in this topic is a reality that seems to meet the health needs of an increasingly aging population and dissatisfied with the current biomedical model. Therefore, the assistance of patients in palliative care requires much more than clinical skills,

as other professional categories must be included in the team, so that it becomes interdisciplinary⁽²⁴⁾.

It should be noted, however, in the analysis of the way of producing each category, which can be uni or multi-professional, it was found in this review a uni-professional prevalence, present in approximately 80% of the productions. This finding is in line with the Brazilian National Academy of Palliative Care (ANCP - Academia Nacional de Cuidados Paliativos) recommendations that the multidisciplinary approach is one of the global principles of palliative care (25). A study (12) emphasizes that if the production in a multidisciplinary way is scarce, this reflects the reality of the care practice, in which each professional performs his functions in an isolated way, without developing multidisciplinary communication.

DISCUSSION

Importance of communication in palliative care

The analysis of the most frequent focuses of publications resulted in 33.7% of appearances on the theme Importance of communication in palliative care. This means that the use of this care strategy is widely disseminated in the scientific community, nationally and internationally.

Studies (A16, A17, A20, A26, A28) show that communication is an essential and central tool. Therefore, the importance of communication is undeniable to ensure that the needs of patients undergoing palliative care and their families are met (A1, A14, A26).

It is worth noting that communication - verbal and non-verbal - and interpersonal relationships form the basis of palliative care (A4, A7), since communication, in the scope of palliative care, is evaluated as an important attribute of attention in the process of finitude of life, either due to the way information is communicated, or because of the emotional support that communication provides to the suffering patient and as an instrument through which the biopsychosocial needs of the patient and family can be identified (A2, A13).

Communication and the establishment of interaction with the family are included in the philosophy of palliative care, mainly through qualified listening, to understand their concerns, their doubts and their anxieties in relation to the conduct adopted by the team in care and in the moments when family intervention is required (A9, A15, A26).

Therefore, communication and an adequate interaction between the team and the family are extremely important to always remain in an open channel, as there is a need to inform, guide and understand the entire patient's disease process experienced by the family, in coping with the illness of his/her loved one (A15).

It should be noted that the role of communication between health professionals and the patient and/or their family members contributes considerably to decision-making about care, especially at the end of life (A6, A3, A10, A4, A5, A8).

Patient care in the process of finitude of life must be individualized, so that conflicts and anxieties can be resolved, and symptoms are minimized (A24, A27, A29). In this sense, there must be a relationship of trust between the patient, the family and the team, so that the family member/caregiver can review their expectations and desires and make a plan after the death of their family member (A4, A20).

A study concluded that communication between the team and the family about the condition and the proximity of the death of their loved one, as well as changes in the therapeutic conduct directly related to it, influenced the way some family members adopted it when waiting for the moment of death, attentive to changes and signs, with each patient's "sigh", making that moment something aggrandizing for their own existence (A9).

A research that investigated the knowledge of end-of-life patients about their diagnosis, prognosis and the possibility of registering their wishes at the end of life in the form of advance directives of will found that adequate communication between the professional, the patients and the family offered dialogue conditions in which themes related to the finitude of life could be approached (A12). Thus, from the perspective of patients and their families, improving communication and the decision-making process is a priority in the care process (A3).

Authors assert that professionals should be open to the use of communication skills that facilitate the empathic encounter. They also should have an active listening attitude and ask questions, with authenticity and congruence, in care for patients under palliative care and their family, since this technique it is useful in decision-making and in the search for new treatment options, in which the professional tries to stimulate the patient, so that his/her psychosocial and spiritual needs are listed, which improves the quality of his/her life and his/her ability to deal with death (A11, A23).

An intervention study revealed that health professionals feel a strong need to improve communication in the team and between patients and professionals and that it is necessary to implement a longitudinal communication approach, in which there is common understanding among all team members and a corresponding attitude that everyone can communicate without any restrictions (A25). However, frank and honest communication between the team and the family is still difficult, as limited communication obliterates the conduct of the members of the palliative team (A18, A19, A21, A22, A28), which may be related to gaps in training professional and/or the professional's little ability to establish effective communication (A21).

Breaking the bad news in palliative care

The thematic focus, breaking the bad news in palliative care, was the one with the second highest frequency, with 26 (30.2%) publications, of the total of articles included, emphasizing the importance of the quality of the process of breaking the bad news by professionals that make up the multidisciplinary health team. Breaking the bad news can change the future of the lives of people involved in palliative care - the patient, the family/caregiver, the community (B19, B12).

Patients and family members involved in the palliative care process report the desire to obtain detailed information about the prognosis, benefits and risks resulting from the treatment (B4, B10, B23), which can help the family to prepare for the loss of the loved one and accepting death (B1, B11). They refer that the communication between the health team and the family, in many circumstances, is confusing or not performed when it comes to the worsening of the disease, the impossibility of curative treatment and the proximity of death (B11).

It is appropriate to point out the responsibility of those who break the bad news, since their announcement generates a strong emotional impact on the patient, almost always, accompanied by fear, anguish and uncertainty. Therefore, a favorable occasion for the professional to establish the role of counselor. Thus, the more careful the way of communicating, the greater the possibility for the patient to understand his/her illness and the treatment process (B19, B2, B14).

Studies have emphasized ethical dilemmas in communicating with the patient about who should give information about bad news, to whom that information should be given and in what situation (B1, B17). However, there is a gap in the discussion about the professional responsible for breaking the bad news and how to do it. In this sense, doctors and nurses are appointed as the professionals who must break the bad news, but they do not catalog their responsibility, showing only the understanding and the importance of this communication (B1, B10, B11, B19, B23).

The Medical Code of Ethics presents guidelines on the communication of information to patients and family members regarding the diagnosis and prognosis of their disease, defining their responsibility to the doctor in the presence of the palliative team (B11, B12).

A study carried out in Georgia, with the aim of examining the communication of doctors and relatives of patients in palliative care, found that, although these professionals deal with death daily, they are not always trained to break the bad news. In addition, doctors did not feel comfortable breaking the bad news to patients or their families about the poor prognosis or nullity of treatment (B3).

Research also highlights the difficulties of doctors, in an emergency situation, when they need to transmit clear and balanced information about the diagnosis of an end-of-life illness (B6, B8, B16, B17, B21).

On the other hand, a study carried out in Brazil observed the concern of doctors in transmitting information about a diagnosis. It was emphasized that they had skills and competences with a view to empathetic, effective and affective communication with the families of patients in palliative care, considering the family's understanding of the terminality and the existence, or not, of family conflicts. The physician's confidence and competence and previous experiences with death in his (social) environment are highlighted to break the bad news to the patient and family (B15, B18).

With regard to nurses, there are few studies in the literature on breaking the bad news, despite being a topic that needs to be better addressed during their academic training, in view of the high number of areas of expertise that this professional will need to communicate unpleasant facts to patients and family members (B12).

Researches concluded that nurses considered information about the bad news to be more acute, complex and frequent, especially when the news is about death or fatal diagnosis. However, they are not aware of the skills to break it (B5, B9, B17, B22, B24, B25).

The findings of the studies indicated that training professionals about communication is of paramount importance, especially with regard to difficult news, given that it provides increased confidence in discussing goals, managing emotions

and expressing empathy with patients and family members in palliative care (B7, B9, B13, B20, B24, B26).

Training professionals/staff for communication in palliative care

With 16 studies (18.6%), the third most frequent focus among the articles included in this scope review was training professionals/staff for communication in palliative care. This finding demonstrates the incipient quantity of productions related to the theme, which may be related to the failure to carry out training intervention studies and/or to the lack of registration and the dissemination of initiatives carried out in national journals, with a high impact factor. Given this evidence, it is necessary to promote training for professionals/staff in the various sectors of health care.

A research points out that training in communication interventions is effective when it contributes to improving doctors' ability to show empathy and discuss emotions with patients and their families. However, although these trainings promote behavioral changes in professionals, including demonstration of empathy, there were more effects in simulated interactions than in real interactions (C6, C15).

Studies carried out in Singapore and the United Kingdom, where palliative care is seen as an emerging medical and nursing specialty, highlight SAGE & THYME - communication skills model, as a highly structured model for teaching patient-centered interactions, as addresses concerns about trust and time and is a useful way to train professionals so that they can improve their practices and maintain effective communication in a health system (C1, C16).

A randomized trial of a workshop based on simulation with medical school interns was carried out with a view to improving communication skills in palliative care (Codetalk). To this end, it found, through standardized patient assessments, better communication skills for interns who received training on general and specific communication skills (C3).

Other studies reinforce the importance of COMFORT communication training, which is an effective online tool to teach specific palliative care communications in various disciplines (C7). It was found that, after training, students' apprehension decreased, and there was a significant improvement in relation to knowledge and confidence in communicating with end-of-life patients and their families (C2).

The communication skills course Geritalk was evidenced in a study (C14) on the effectiveness of this course, comparing the pre- and post-course real-time assessment of participants who conduct family gatherings. The results showed that this training was effective in teaching fundamental communication skills necessary to conduct conversation between the team and the family, as well as the development of advanced communication skills.

Thus, it is emphasized that the simulation-based learning experience is being used to teach palliative communication skills at the end of life. However, the lack of standardization, inadequate assessment methods and limited exposure to the entire interprofessional team make it difficult to identify and disseminate validated best practices (C15).

In another study, it was found that communication at the end of life was more taught in the context of courses on palliative care, using a mixture of didactics, reflection, discussion and role dramatization (C9). The educational activity was also listed in a study, which revealed that it enabled the development of critical thinking and that the participants take ownership of communication strategies and organization of the care provided to the patient in need of palliative care (C12, C13).

It is worth emphasizing that few recommendations for training communication skills in palliative care were found in articles on this thematic approach and few studies have evaluated how these training programs impacted patients and/or their families (C4, C10).

Thus, communication education is a vital element, albeit absent (C5, C8, C11). The programs must be offered in the academic and work environment, in order to address this gap in the necessary competence, particularly in the context of palliative care.

Communication strategies in palliative care

The fourth theme discussed in the articles that comprised this review was about communication strategies in palliative care, whose focus was less representative in studies (17.4%). It denotes the reality of a scarce literature, nationally and internationally, about communication strategies in palliative care, perhaps justified by the incipient approach of the subject in undergraduate courses, which contributes to the fact that students are not very interested in the topic, and because this so-important tool is not used in the care process and, particularly, in palliative care.

Communication manifests itself in the relationship between the patient and the health team in several ways and can be verbalized or not. In verbal communication, the emission of words, notes and records in medical records is configured. Through it, the health professional can appropriate several techniques to establish a positive interpersonal relationship with the end-of-life patient, such as promoting empathy and an environment of interaction; repeating the information whenever necessary; making sure that communication has been understood; knowing how to listen; using an appropriate tone of voice, being sincere and transparent; making time available and make yourself available; keeping a consistent speech and using colloquial language (D9, D11, D15).

A study corroborates this statement, by verifying that nursing professionals use empathy with honesty in their conversations, repeating information whenever necessary and giving confidence to the patient in palliative care and his/her family (D1).

Authors contemplate the conversation technique (D1, D6), the planning discussion about advanced care (D8), storytelling (D4, D11) and family and group dynamics (D11, D13), as valuable ways to improve communication about end-of-life care. They also found that the experience of talking about existential issues in a supportive environment helps professionals to feel comfortable when advising patients close to death (D1, D2).

Family meetings were also emphasized as a communication strategy to meet the needs of patients under palliative care and their families, but there is a lack of evidence to support family meetings in this context of inpatient care (D2).

With regard to communication technologies, they were addressed in two studies on this topic, which mentioned that they

aim to improve the quality of life in terminality, minimizing social isolation and facilitating social connection (D3, D5).

A study that aimed to explore the acceptability of patients in a palliative care unit, regarding the use of internet-based communication and information technologies, showed that hospitalized patients and their families talked about the challenges of maintaining contact with family and friends, investigating ways to benefit the life and care of patients undergoing palliative care (D5). Thus, a cross-sectional design was carried out, which found that patients in palliative care and their families used computer technology - iPad or laptop - to keep in touch with family and friends, search for information and/or perform tasks, enabling sharing important decisions and access to the outside world (D3). Another strategy demonstrated in a research was a communication support program, the Communication Support Program (CSP), with a view to facilitating communication and improving the patient's quality of life in palliative care (D7).

As for non-verbal communication, it is one in which information is transmitted through gestures, facial expression, body orientations, postures, among others. This type of communication enhances the dissemination of the message and reduces the difficulties of verbalizing, especially in palliative care (D11, D12, D15).

In this context, humanization is essential when taking care of an end-of-life patient, as care must be directed towards him/her, and not towards his/her pathology, and listening and the therapeutic use of silence are essential in this phase. Listening is an emotional, active and complex cognitive technique that emerges from auditory perception and considers the variables 'attention', 'interest' and 'motivation' (D10, D13, D14).

A study carried out with a nurse from the Home Care Service (HCS) (D11) highlighted, in addition to verbal communication strategies, affective touch, attentive listening, looking and writing and reported that understanding and perception of feelings, suspicions and afflictions, as well as understanding the importance of touch, gestures, expressions, looks and symbolic language are essential for the patient and family who experience the finitude of life.

As for music therapy, it was mentioned by four professionals in this study as a communication strategy. Music is a complementary therapy to conventional treatments, which is part of the communication process and helps to recover patients without the possibility of a cure, given that it allows them to recall the anguish and suffering experienced and shared (D11).

Therefore, the communication involved in the study's approaches differs from information. It is not just about transmitting information, but also looking at how messages are transmitted. It is about expressing yourself with words, postures, attitudes (verbal and non-verbal communication) and messages that reveal attention and care. However, the study showed that, when it comes to patients in palliative care, professionals link communication, often to negative news.

Study limitations

This study presented as a limitation the inclusion of studies in only three languages (English, Portuguese, and Spanish) and the inclusion of studies from the four selected databases (LILACS, BDENF, Index Psi and MEDLINE), which may have limited access to other relevant data.

Contributions to nursing

Based on the results of this review, it was possible to identify the main themes about communication in palliative care, which can bring contributions to the implementation of the theme, in different institutional contexts, and inspire the realization of future studies that demonstrate the ability of professionals to create communication strategies. Also important are studies that aim to know and analyze professional practices, essentially those of nursing, in order to identify and disseminate successful interventions.

FINAL CONSIDERATIONS

The findings revealed a significant number of articles related to communication in palliative care, which mainly address topics such as the importance of communication, communication strategies, breaking the bad news, and training professionals/ staff for communication in palliative care. The profile traced through the results and discussed in this study, as well as the low level of evidence, conjecture the practice of palliative care, still largely performed in an empirical way and without theoretical-scientific basis.

Associated with the limited knowledge on this subject, the inability to carry out actions through communication is characterized as a barrier to good quality care, involving the varied needs of human beings. This review showed that communication strategies are seldom used and that little training is done to use them. From this survey, it is possible to affirm that professionals need to be better informed about 'palliative care and communication', based on the increase in chronic diseases, and that knowing communication strategies is mandatory when seeking a humanized and good quality health care.

Therefore, given the results, it is expected that the mapping on communication in palliative care will motivate new studies, in order to configure a scenario of qualified scientific production and with more strength of evidence in the area, to present contributions beyond the thematic awareness and serve as support to reformulate and restructure related communication practices. It is hoped that, in this way, it will be possible to improve, in addition to scientific production, assistance in palliative care and communication.

REFERENCES

 Lima CP, Machado MA. Main caregivers facing death experience and its meanings. Psicol Ciênc Prof. 2018;38(1):88-101. https://doi. org/10.1590/1982-3703002642015

- World Health Organization (WHO). Cancer: WHO definition of palliative care [Internet]. 2002. [cited 2019 Apr 19]. Available from: https://www.who.int/cancer/palliative/definition/en/
- 3. Caldas GHO, Moreira SNT, Vilar MJ. Palliative care: a proposal for graduate education in medicine. Rev Bras Geriatr Gerontol. 2018;21(3):261-71. https://doi.org/10.1590/1981-22562018021.180008
- 4. Luiz MM, Netto JJM, Vasconcelos AKB, Brito MCC. Palliative nursing care in the elderly in UCI: an integrative review. Rev Fund Care. 2018:10(2):585-592. https://doi.org/10.9789/2175-5361.2018.v10i2.585-592
- Santos EAA. Barriers associated with palliative care in dementia: a review of the literature. Geriatr Gerontol Aging. 2018;12(2):105-112. https://doi.org/10.5327/Z2447-211520181800014
- 6. Galvão MIZ, Borges MS, Pinho DLM. Interpersonal communication with oncological patients in palliative care. Rev Baiana Enferm. 2017;31(3): e22290. https://doi.org/0.18471/rbe.v31i3.22290
- 7. Paula TA, Santos TN, Silva DG, Bueno IS, Souza LP, Cauduro LB, et al. A comprehensive review on palliative care. Acta Med. 2018;39(1):87-101. https://doi.org/10.3109/09540261.2013.868788
- 8. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Meth. 2005;8(1):19-32. https://doi.org/10.1080/13 64557032000119616
- 9. Ferreira LL, Azevedo LMN, Salvador PTCO, Morais SHMM, Paiva RMP, Santos VEP. Cuidado de enfermagem nas infecções relacionadas à assistência à saúde: scoping review. Rev Bras Enferm. 2019;72(2):498-505. https://doi.org/10.1590/0034-7167-2018-0418
- 10. Lourenço RG, Fornari LF, Santos DLA, Fonseca RMGS. Intervenções comunitárias relacionadas à violência entre parceiros íntimos adolescentes: revisão de escopo. Rev Bras Enferm. 2019;72(1):277-86. https://doi.org/10.1590/0034-7167-2018-0586
- 11. Salgueiro-Oliveira AS, Costa PJS, Braga LM, Graveto JMGN, Oliveira VS, Parreira PMSD. Health professionals' practices related with tourniquet use during peripheral venipuncture: a scoping review. Rev Latino-Am Enfermagem. 2019;27:e3125. https://doi.org/10.1590/1518-8345.2743-3125
- Mendes DIA, Ferrito CRAC, Gonçalves MIR. Intervenções de Enfermagem no programa Enhanced Recovery After Surgery®: scoping review. Rev Bras Enferm. 2018;71(Suppl6):2824-2832. https://doi.org/10.1590/0034-7167-2018-0436
- 13. Sanches KS, Rabin EG, Teixeira PTO. The scenario of scientific publication on palliative care in oncology over the last 5 years: a scoping review. Rev Esc Enferm USP. 2018;52:e03336. https://doi.org/10.1590/s1980-220x2017009103336
- 14. Santos CMC, Pimenta CAM, Nobre MRC. The PICO strategy for the research question construction and evidence search. Rev Latino-Am Enfermagem. 2007;15(3):508-11. https://doi.org/10.1590/S0104-11692007000300023
- 15. Brun CN, Zuge SS. Revisão sistemática da literatura: desenvolvimento e contribuição para uma prática baseada em evidências na enfermagem. In: Lacerda MR, Costenaro RGS, (Orgs.). Metodologias da pesquisa para a enfermagem e saúde. Porto Alegre: Moriá; 2015. p. 77- 98.
- 16. Stetler CB, Morsi D, Rucki S, Broughton S, Corrigan B, Fitzgerald J, et al. Utilization-focused integrative reviews in a nursing service. Appl Nurs Res. 1998;11(4):195-206. https://doi.org/10.1016/S0897-1897(98)80329-7
- 17. Moher D, Liberati A, Tetzlaff J, Altman DG. PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. J Clin Epidemiol [Internet]. 2009 [cited 2019 May 5];62(10):1006-12. Available from: http://www.systematicreviewsjournal.com/content/4/1/1
- 18. Hawley P. Barriers to access to palliative care. Palliat Care. 2017;10:1178224216688887. https://doi.org/10.1177/1178224216688887
- Di Bitetti MS, Ferreras JA. Publish (in english) or perish: the effect on citation rate of using languages other than english in scientific publications. Ambio. 2016;46(1):121-7. https://doi.org/10.1007/s13280-016-0820-7
- Palmeira HM, Scorsolini-Comin F, Peres RS. Cuidados paliativos no Brasil: revisão integrativa da literatura científica. Aletheia [Internet]. 2011 [cited 2019 Apr 19];35(36):179-89. Available from: http://pepsic.bvsalud.org/scielo. php?script=sci_arttext&pid=S1413-03942011000200014&Ing=pt
- Alves AMPM, Costa SFG, Fernandes MA, Fernandes MA, Batista PSS, Lopes MEL, Zaccara AAL. Cuidados paliativos e comunicação: estudo bibliométrico. Rev Pesqui: Cuid Fundam. 2019;11(n.esp):524-32. https://doi.org/10.9789/2175-5361.2019.v11i2.524-532
- 22. Fernandes MA, Costa SFG, Morais GSN, Duarte MCS, Zaccara AAL, Batista PSS. Cuidados paliativos e luto: um estudo bibliométrico. Esc Anna Nery. 2016;20(4):e20160102. https://doi.org/10.5935/1414-8145.20160102
- 23. Dahlin C. Palliative care: delivering comprehensive oncology nursing care. Semin Oncol Nurs. 2015;31(4):327-37. https://doi.org/10.1016/j. soncn.2015.08.008
- 24. Abel J, Kellehear A. Palliative care reimagined: a needed shift. BMJ Support Palliat Care. 2016;6(1):21-26. https://doi.org/10.1136/bmjspcare-2015-001009.
- Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos [Internet]. 2. ed. São Paulo: ANCP; 2012[cited 2019 Apr 19].
 Available from: http://biblioteca.cofen.gov.br/wp-content/uploads/2017/05/Manual-de-cuidados-paliativos-ANCP.pdf