

Definitions for “palliative care”, “end-of-life” and “terminally ill” in oncology: a scoping review

Definiciones para “cuidados paliativos”, “final de vida” y “enfermedad terminal” en oncología: scoping review

Definições para “cuidados paliativos”, “final de vida” e doença terminal em oncologia: scoping review

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Received: 02/19/2020

Accepted: 10/07/2020

Abstract: Objective: to identify and map the definitions for palliative care, end of life, and terminally ill in the oncology literature. Materials and method: scoping review guided by Joanna Briggs Institute recommendations. We analyzed original articles, published between 2012 and 2017, indexed in the databases Pubmed, Web of Science and Scopus. The data collection resulted in 51 articles selected for analysis. Also, we have consulted the websites of 25 palliative care societies from countries best ranked in The Economist’s Quality of Death Ranking. The data were analyzed through descriptive statistics, and summary of the themes, in this case the definitions. Results: terminally ill is a disease with a prognosis of lifetime ranging between hours and months, there is clinical worsening, functional decline, and presence of metastases. Palliative care aims to promote quality of life and dignity. End of life is the period of up to 12 months before death. Conclusions: we constructed synthesis and definitions for the concepts investigated. Thus, it was possible to contribute to the adoption of a standardized language in care and investigations with cancer patients in end-of-life.

Keywords: Palliative care; terminally ill; hospice care; medical oncology; qualitative research

Resumen: Objetivo: Identificar y mapear las definiciones de cuidados paliativos, fin de vida y enfermedad terminal en la literatura en oncología. Materiales y método: *scoping review* basada en

los supuestos del *Joanna Briggs Institute*. Se analizaron 51 artículos originales, publicados entre 2012 y 2017, indexados en las bases de datos *Pubmed*, *Web of Science* y *Scopus*. Se consultaron los sitios web de 25 sociedades de cuidados paliativos de los países mejor clasificados en *The Economist's Quality of Death Ranking*. Los datos fueron analizados a través de estadística descriptiva y se resumieron por temas, en este caso, las definiciones. Resultados: enfermedad terminal se trata de una enfermedad con tiempo de vida que oscila entre horas y meses; hay un empeoramiento clínico; deterioro funcional y la presencia de metástasis. Los cuidados paliativos tienen por propósito la calidad de vida y la dignidad. El final de la vida comprende el período de hasta 12 meses antes de la muerte. Conclusiones: se ha construido síntesis y definiciones para los conceptos investigados, siendo posible contribuir para adopción de un lenguaje estandarizado en los cuidados e investigaciones junto a los pacientes oncológicos en fin de vida.

Palabras claves: Cuidados paliativos; enfermedad crítica; cuidados paliativos al final de la vida; oncología médica; investigación cualitativa

Resumo: Objetivo: identificar e mapear as definições de cuidados paliativos, final de vida e doença terminal na literatura em oncologia. Materiais e métodos: *scoping review* baseada nas recomendações do *Joanna Briggs Institute*. Analisamos artigos oriundos de estudos primários, publicados entre 2012 e 2017, indexados nas bases de dados *Pubmed*, *Web of Science* e *Scopus*. Foram selecionados 51 artigos que atenderam aos critérios de inclusão e exclusão. Também foram consultados websites de 25 sociedades de Cuidados Paliativos dos países com melhor classificação no índice de qualidade de morte da revista *The Economist*. Os dados foram analisados por meio de estatística descritiva e síntese dos temas, no caso, as definições. Resultados: doença terminal é aquela com tempo de vida que varia entre horas e meses, há piora clínica, deterioramento funcional e metástases. Cuidados Paliativos têm por finalidade a promoção da qualidade de vida e a dignidade. Final de vida é o período de até 12 meses que antecede a morte. Conclusões: construiu-se síntese e definições para os conceitos investigados, sendo possível contribuir para adoção de uma linguagem padronizada nos cuidados e investigações junto aos pacientes oncológicos em final de vida.

Palavras-chave: Cuidados paliativos; estado terminal; cuidados paliativos na terminalidade da vida; oncologia médica; pesquisa qualitativa

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Introduction

The demographic and epidemiological transition, made possible by the control of infectious diseases and reduction of maternal and child mortality, changed the clinical population profile,

making chronic noncommunicable diseases prevalent in worldwide. With the natural evolution of the disease, at a certain moment, the modifying treatment is no longer effective, resulting in progression, loss of functionality and death. This period, from the moment the disease no longer responds to the treatment that intends to modify it until death, is defined by different terminologies: terminality, terminal illness, terminal care, end-of-life, actively dying, transition of care, and palliative care (1,2,3). The clinical terms have administrative, clinical and academic repercussions, as they imply the planning of care to be offered to the patient and family (4).

In the literature, especially in oncology and palliative care, there is no consensus on the definition of terminologies commonly used to refer to the final stage of illness and the end-of-life (1,3). Defining such terminologies can help in the qualification of communication between health professionals, researchers, and in the elaboration of public policies at the end-of-life. A review study identified a lack of consensus on the definition of "end-of-life," "terminal illness," "end-of-life care," "actively dying," "transition of care" (1). The terms "end-of-life," "terminal illness," "end-of-life care" share a similar meaning: a progressive disease with a prognosis of months or days. This study did not evaluate, for example, publications and associations from countries in which the emergence and growth of palliative care, such as Latin American countries, is present.

Considering the lack of consensus on definitions of terminology used in the late stages of illness and life, as well as the increasing publication of end-of-life public policies and programs and palliative care in countries of the Asian and American continents, it is relevant to identify how such terminologies are used in scientific publications and knowledge societies in the area. In addition, recently the *International Association for Hospice and Palliative Care* (IAHPC) proposed to the World Health Organization to update the definition of palliative care.

Thus, the objective of this study was to identify and map the definitions for palliative care, end of life, and terminally ill, used in oncology literature.

Materials and Method

We defined a scoping review based on the recommendations of the *Joanna Brigs Institute* (JBI) (6). A scoping review can be used to map key concepts that underlie a research area. For this study, we prepared a literature review protocol. It was evaluated by two external researchers, considering the population, context, and concepts (PCC) to be investigated. Thus, the research questions were: What concepts of palliative care, end-of-life, and terminal illness are, in adult oncology, adopted by leading palliative care societies in America, Asia, Europe, Africa, and Oceania? What concepts of palliative care, end-of-life, and terminal illness, in the adult area, adopted in qualitative and quantitative approach research in the field of oncology?

Selection criteria

Regarding publications in journals, the inclusion criteria were: original articles and reflection articles published between January 2012 and December 2017, in English, French, Portuguese, and Spanish. For the selection of the original articles, we considered those in which the study population were people/patients aged 18 years old or older, suffering from cancer disease. We excluded editorials, theses, monographs, abstracts at scientific events, experience reports, review articles, and duplicate articles. Regarding Palliative Care Societies, we considered those from the five continents, from the adult area, with an updated web page, which countries presented the best position in *The Economist's* report on the quality of death (7).

Literature Search

We searched articles through double consultation and double collection in PubMed, Scopus, and Web of Science databases. For this purpose, associated with the Boolean operator AND, the Medical Subject Headings (MeSH) terms "Terminally ill"; "Palliative Care"; "Oncology Service, Hospital." We selected articles after a consensus between the pairs of researchers, who identified the concepts. At first, we read of the "method" section. In the second stage, we read articles in full to determine the inclusion of studies for analysis. In order to ensure the quality of this step, we followed the principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA). In Figure 1, we summarize the PRISMA adapted to our study.

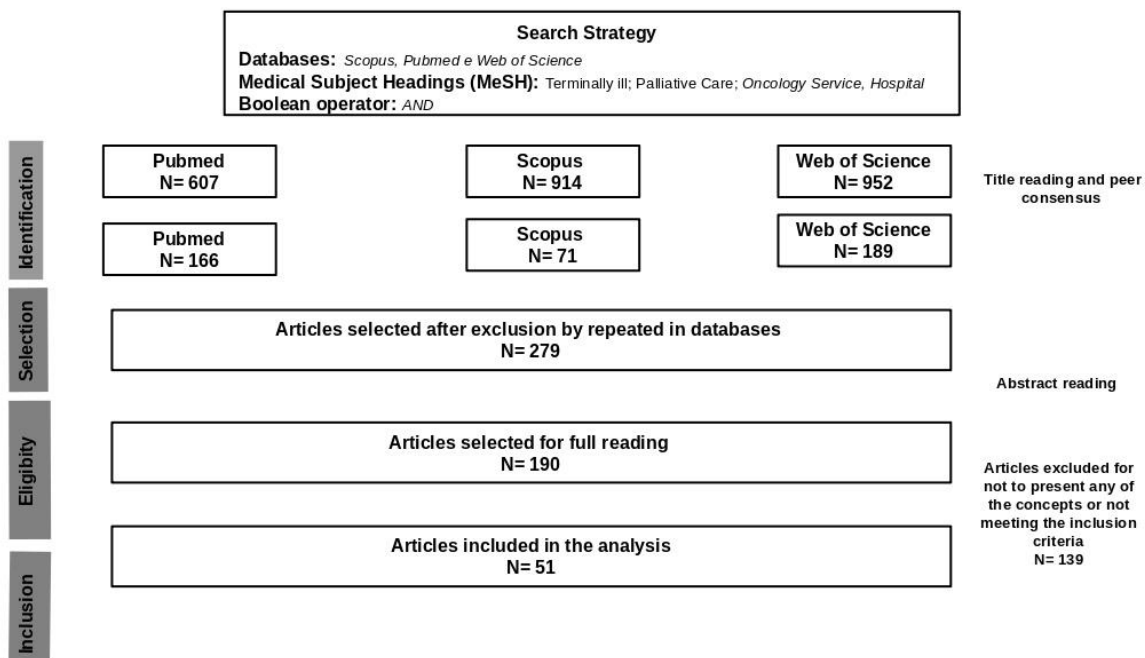


Figure 1. Search strategy/ Own creation, 2020.

Organization Web site Search

Concerning palliative care societies, we consulted, between October and November 2018, the introductory pages of each website, and sought to identify glossaries that could indicate the meaning of the terminologies used by societies in their atlases, manuals or guides.

Data Extraction and Analysis

We organized the data in a spreadsheet program (LibreOffice Calc), which included: article title, authors, area, journal, journal impact factor, year of publication, objectives, method, number of study participants, the definition given for palliative care and/or terminally ill and/or end-of-life. We synthesized the definitions by simple frequency and percentage.

Results

Literature Search

Of the 51 articles analyzed, 46 were quantitative and five qualitative. Of these, seven presented fragmented results from the same study (8, 9, 10, 11, 12, 13, 14). Regarding the years of publication, 2014, 2016, and 2017 had more articles published, totaling, respectively, 14, 12, and 10 publications in the period. Of the areas to which the research was linked, 25 came from Medicine, 13 from multidisciplinary, six from Nursing, three from Psychology, two from Pharmacy, and one from Social Sciences.

Regarding countries, the following stands out Australia (10%), Canada (12%), South Korea (10%), United States (10%), Netherlands (8%), and Taiwan (12%). *Journal of Pain and Symptom Management* (16%), *Palliative Medicine* (14%), *American Journal Of Hospice & Palliative Medicine* (6%), *BMC Palliative Care* (6%), and *Palliative and Supportive Care* (6%) were journals with most publications.

About the definitions: “end-of-life” was characterized in five studies, four quantitative and one qualitative; “palliative care” was defined in 15 studies, 11 quantitative and four qualitative and “terminally ill” appeared in 35 studies, 31 quantitative and five qualitative. (Appendix 1) (5, 8, 9, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 36, 34, 42, 54, 55, 56). Among those, three articles presented two definitions. Two of them for “terminally ill” and “end-of-life” (5,9), another (36) presented for “palliative care and “terminally ill”. For this reason, in Appendix 1, we presented 55 definitions, although 51 articles have been analyzed.

Organization Web site Search

We consulted the websites of 25 Palliative Care Societies, of which 84% defined "palliative care," 24% defined "end-of-life," and 12% defined "terminally ill." Societies from countries with the lowest ranking in The Economist, located mainly on the American and African continents, presented fewer definitions for the three concepts. Three institutions featured one page on social network Facebook as an official website of the institution. Other societies had no website for a consultation. When defined "palliative care," in general, this makes reference to the definitions adopted by the World Health Organization or the Continental Society for the Area (Appendix 2).

The concepts with the most definitions were "terminally ill" and "palliative care." "Terminally ill" is linked to a prognosis defined by a certain amount of months, days, or even hours of life. It is also associated with an incurable disease. Palliative care appears as specialized care provided by a multidisciplinary team, aimed at dignity and quality of life, through pain control and other symptoms. This care is also often related to diseases that no longer respond to modifying treatment and are life-threatening to the patient. Figures 2, 3, and 4 presents a concept map with the standard definitions linked to the concepts.

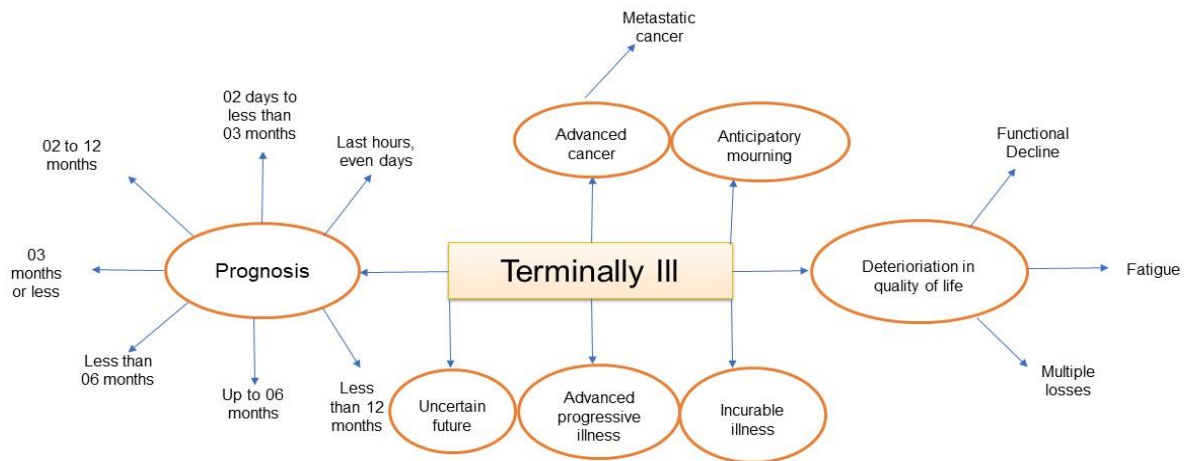


Figure 2. Conceptual map for terminally ill. Own creation, 2020.

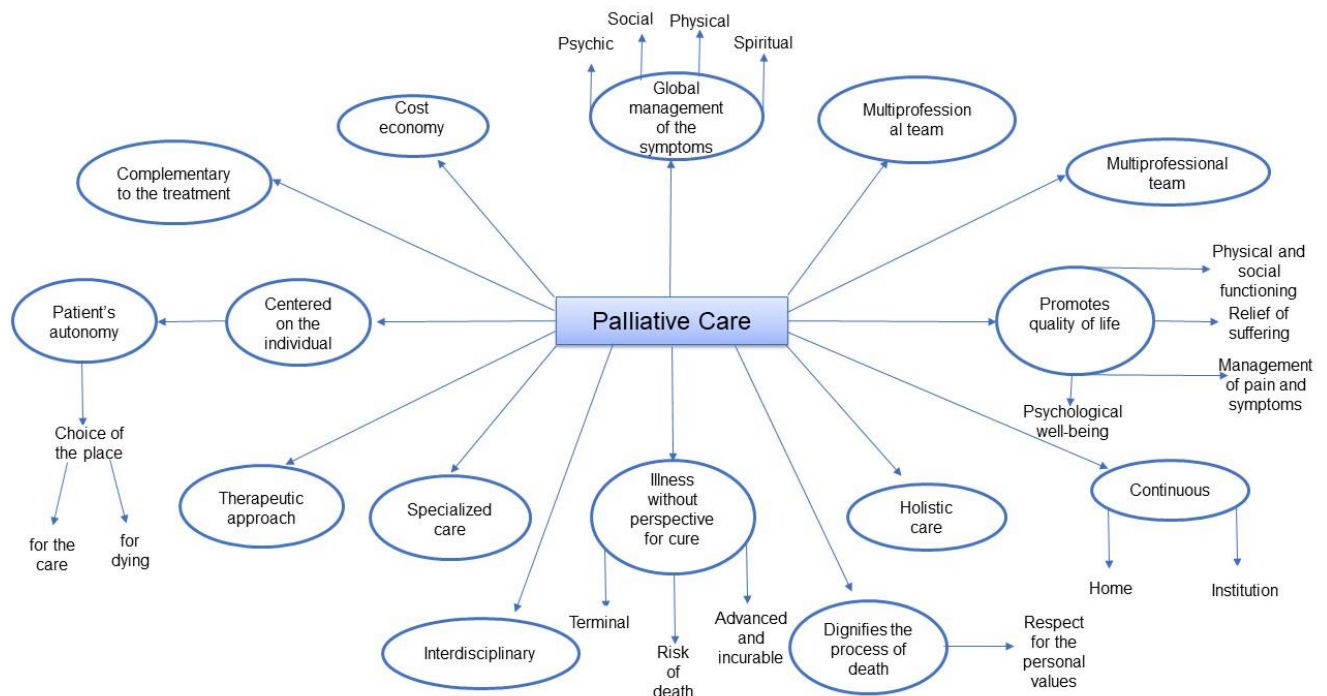


Figure 3. Conceptual map for palliative care/ Own creation, 2020.

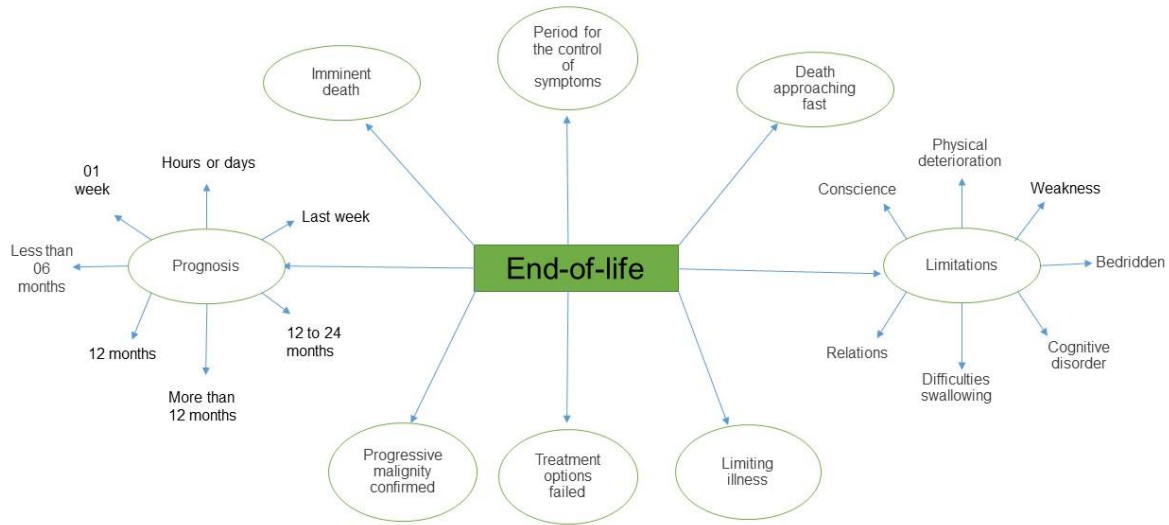


Figure 4. Conceptual map for end-of-life/ Own creation, 2020.

In table 1, we summarize and present a consensus of definitions for the concepts analyzed.

Table. 1 Definitions for “terminally ill”, palliative care and end-of-life in oncology	
Terminally Ill	A disease that no longer responds to modifying treatment associated with the presence of metastases, functional decline, and worsening of quality of life. Life expectancy is less than 12 months.
Palliative care	An interdisciplinary approach centered-patient with advanced or terminal illness and his family. Palliative care aims to provide quality of life and relief from suffering through overall symptom control and respect for values and beliefs.
End-of-life	Stage of a disease in which the possibility of death becomes real and life expectancy is less than 12 months. There is rapid physical and psychological deterioration, as well as increased symptoms.

Source: Own creation, 2020.

Discussion

In the international literature, quantitative approach studies are the ones that present the most definitions for situations involving palliative care and end-of-life. Especially when it comes to delimiting population and sample. This fact may indicate that the methodological designs linked to this approach tend to present more rigorous selection criteria for research participants. The need arises for qualitative studies to improve the inclusion criteria in the selection of study participants, based on definitions, terminologies, and concepts that can ensure greater validity and reliability to the results. Defining terms, establishing criteria, as well as adopting standardized language favors not only the methodological aspects of research but the transfer of knowledge to clinical practice, helping to consolidate knowledge areas (57).

Medicine stands out as the area of knowledge that has published most studies, demonstrating the growing appropriation of this knowledge about palliative care. Last years, palliative care has moved between a multidisciplinary domain and a new area of medical expertise (58).

Countries with the most publications presenting definitions of palliative and/or end-of-life care and/or terminal illness - Australia, Canada, South Korea, the United States, the Netherlands, and Taiwan - are also countries that rank well for refers to end-of-life quality in *The Economist* survey. In such countries, the quality of services provided by easy access to opioids, psychological support, and bereavement services, the appropriate number of specialists in the field, and community participation also help these countries to provide satisfactory Palliative Care (7). Countries with good access to this type of care have a high Human Development Index (HDI), i.e., have a high life expectancy, good access to education, and high gross national income (59).

The United States of America, for example, occupies the 13th position in the HDI world ranking, and the life expectancy of the population is 79.5 years old (60). An aspect that can contribute to the good development of palliative care in the USA is the presence of legislation on patients' rights at the end of life. As well as the presence of reference centers and associations on the subject, which is recognized worldwide. Nevertheless, limitations in symptom control (fatigue, ascites, dyspnea), lack of investment in research in the area, as well as the drop in the number of professionals, notably doctors and nurses, at different levels of care are barriers to integration and execution of palliative care in the UShealth care system (60).

Canada occupies the 12th position in the same ranking; the population has a life expectancy of 82.5 years old. The Canadian health care system provides for a structure based on access, quality, and long-term sustainability. In addition, this agreement is aimed at reforms in primary health care, information technology support, coverage for home care services, and facilitated access to medical and diagnostic equipment (61). In 2017, the Canadian Ministry of Health introduced a law providing for the development of palliative care structures (62).

Taiwan, a top-rated Asian country in *The Economist* ranking, since 2000, has patient rights legislation (63). From 2015, Taiwanese law provides that anyone with cognitive ability, over the age of 20, may draw up a document in the form of advance directives or advanced care plan, refusing to receive certain measures that have no clinical benefit, which may result in suffering (64).

When it comes to knowledge societies, Latin American and African countries still have weaknesses in structure, legislation, public policies, programs, and civil and health organizations in palliative care. A study (65) published in 2019 found that developing countries, i.e., those with

medium to High Human Development Index (HDI), present more significant challenges in implementing palliative care practice. As well as countries with high infant and child mortality rates, infectious diseases, high rates of political corruption, and fragility in democracy. In such countries, the priority of health investments is for diseases that have not yet been controlled or eradicated and are the cause of high mortality rates. Countries with limited palliative care services also had difficulties in accessing other health services and challenges in promoting different forms of well-being (66).

Knowledge societies in the United Kingdom, Germany, Australia, Switzerland, and Panama have definitions for Palliative Care and End of Life. Panamanian society is the only one among Latin American countries to present the definition for such concepts. The French Society for Palliative Care and Follow-up is the only one that provides definitions for the three concepts investigated in this study. France has a specific legislation for end-of-life behaviors, such as the elaboration of advance will directives, procedures for the implementation of continuous sedation until death, and for the limitation or withdrawal of treatments. In this country, palliative care is a recognized medical specialty. Furthermore, there are pedagogical training projects for doctors and nurses, oral opioids are available, and doctors of different specialties can prescribe them. These factors favor the development and consolidation of palliative care in France (67).

To define palliative care, the criteria used were advanced, terminal, incurable and severe diseases. In addition, quality of life was often related to this type of care, symptom management, specialized team care, family support, and coping with psychosocial and spiritual symptoms. The lack of consensus on the definition of palliative care is related to the conflicts that focus, especially when the specialized teams start the approach. Some professionals believe that a more advanced follow-up of the disease is necessary. Others think that the introduction of palliative care should occur when the disease is diagnosed, and others when it no longer responds to modifying treatment. In this regard, confusion is still evident between palliative care and supportive care. However, it is possible to observe that the authors agree with the objectives of such care. Lack of consensus hinders government funding and the opening of new programs in the area (68).

Regarding end-of-life, different criteria were defined to conceptualize it, which were associated with severe physical and cognitive deterioration, tumor progression, and malignancy. It was often associated with the last days or hours of life and in some prognostic literature less than six or twelve months of life (9, 54, 55, 56). However, clinicians often stipulate prognoses intuitively, so they are inaccurate. Some scales aid this prognosis, but they depend on the patient, settings, and physicians. These uncertainties cause harm to both families and patients, given the expectations raised about this final period of life (69). The terminal illness was linked to different prognoses, ranging from days to less than one year of life. This term has also been associated with incurable, progressive diseases, and a period of intense deterioration in the quality of life. However, some authors consider that to classify a patient as a terminal; it is necessary to have knowledge about the estimated survival period for a given disease and to know the prognosis of most lethal chronic diseases. Other authors also state that the terminal condition is associated with the impossibility of restoring health and that in the absence of artificial procedures, death is achieved (13, 14, 18, 20, 21, 40).

A limitation of this study is the language barrier. We consulted only articles and websites of societies with English, Spanish, Portuguese, and French. Moreover, we may have been misinterpreted some websites and even some articles. Due to possible translation problems, as the authors and proofreaders who selected the documents have Portuguese as their native language.

Another limitation is the exclusion of review article. The studies with this methodological approach may have identified other terminologies and concepts that could endorse the definitions found. Finally, having restricted the area of oncology to search may also be a limiting factor of the conclusions presented.

Conclusions

In this article, we identified and mapped the definitions for palliative care, end-of-life, and terminally ill in oncology literature. The definitions were linked to the rapid progression of the disease, the decline in functionality, and the estimated lifetime ranging from to 12 months. There was a lack of consensus on definitions, even in the area of oncology, which has well-defined criteria and guidelines.

The implications of this study for research concern the possibility of standardizing terminologies, as well as helping to define inclusion and exclusion criteria of patients in other research, especially those with a qualitative approach. Likewise, it contributes to the consolidation of the area, favoring the adoption of common vocabulary in the academic and scientific circles when referring to patients with a terminally ill, at the end-of-life or in palliative care.

The implications for the practice are related to the fact that clarifying and defining terminologies can qualify palliative care. That way, it is possible to elaborate individualized care plans based on a common language adopted among all members of the interdisciplinary team.

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How to cite: Cordeiro FR, Oliveira SG, Giudice JZ, Fernandes VP, Oliveira AT. Definitions for “palliative care”, “end-of-life” and “terminally ill” in oncology: a scoping review. *Enfermería: Cuidados Humanizados*. 2020; 9(2): 205-228. Doi: <https://doi.org/10.22235/ech.v9i2.2317>

Authors' participation: a) Conception and design of the work; b) Data acquisition; c) Analysis and interpretation of data; d) Writing of the manuscript; e) Critical review of the manuscript. FRC has contributed in a,b,c,d,e; SGO in b,c,e; JZG in b,c,d,e; VPF in b,e; ATO in b,c,d.

Scientific editor in charge: Dra. Natalie Figueredo

Appendix 1. Definitions for terminally ill, palliative and end-of-life care in oncology publications

Reference	Type of study	Proposed definitions
Definitions - Terminally ill		
Miljkovic <i>et al. Journal of Palliative Medicine</i> , 2015 ⁽¹⁵⁾	Quantitative study	Terminally ill: advanced cancer with projected life expectancy in less than a year.
Yan Ho <i>et al. Trials/BMC</i> , 2017 ⁽¹⁶⁾	Quantitative study	Terminally ill: life expectancy less than six months.
Mowll <i>et al. Palliative & Supportive Care</i> , 2015 ⁽¹⁷⁾	Quantitative study	Terminally ill: cancer diagnosis and prognosis from 2 to 12 months.
Houmann <i>et al. Palliative Medicine</i> , 2014 ⁽¹⁸⁾	Quantitative study	Terminally ill: incurable disease.
Belanger <i>et al. International Journal of Palliative Nursing</i> , 2015 ⁽¹⁹⁾	Quantitative study	Terminally ill: prognosis of approximately 3 months or less, according to the attending physician.
Wright <i>et al. BMJ</i> , 2014 ⁽⁵⁾	Quantitative study	Terminally ill: metastatic cancer that progresses on at least one chemotherapy regimen and has a formulated medical prognosis of six months or less.
Chang <i>et al. Asian Pacific Journal of Cancer Prevention</i> , 2013 ⁽²⁰⁾	Quantitative study	Terminally ill: advanced progressive disease that in medical opinion is refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy or hormone therapy) and is likely to die within months.
Lee <i>et al. Palliative & Supportive Care</i> , 2015 ⁽²¹⁾	Quantitative study	Terminally ill: progressive disease and that, according to medical advice, death may occur within a few months due to general prostration, refusal of future chemotherapy or unresponsiveness of the disease to conventional anticancer therapy.
Kao <i>et al. Journal of Pain and Symptom Management</i> , 2014 ⁽²²⁾	Quantitative study	Terminally ill: patients who were unlikely to survive for more than six months based on medical judgment.
Sinclair <i>et al. Journal of Pain and Symptom Management</i> , 2016 ⁽²³⁾	Qualitative study	Terminally ill: life expectancy less than six months.
Huang <i>et al. Support Care Cancer</i> , 2014 ⁽²⁴⁾	Quantitative study	Terminally ill: incurable cancer with a prognosis of less than 3 months of life.
Ho <i>et al. Death Studies</i> , 2013 ⁽²⁵⁾	Qualitative study	Terminally ill: life expectancy not over 6 months.

Vuksanovic et al. <i>Journal of Pain and Symptom Management</i> , 2017 ⁽²⁶⁾	Quantitative study	Terminally ill: advanced disease with a life expectancy of less than 12 months.
Rosenfeld et al. <i>Social Science & Medicine</i> , 2014 ⁽²⁷⁾	Quantitative study	Terminally ill: advanced cancer and life expectancy of 6 months or less.
Kim et al. <i>Psycho-Oncology</i> , 2013 ⁽²⁸⁾	Quantitative study	Terminally ill: estimated survival time of a few months.
Julião et al. <i>Palliative and Supportive Care</i> , 2017 ⁽²⁹⁾	Quantitative study	Terminally ill: prognosis of 6 months or less.
Walczak et al. <i>International Journal of Nursing Studies</i> , 2017 ⁽³⁰⁾	Quantitative study	Terminally ill: prognosis is < 1 year of life.
Tang et al. <i>Palliative Medicine</i> , 2014 ⁽¹¹⁾	Quantitative study	Terminally ill: does not respond to curative treatment.
Franken et al. <i>British Journal of Clinical Pharmacology</i> , 2017 ⁽⁸⁾	Quantitative study	Terminally ill: survival of more than 2 days and less than 3 months. The last hours until days before death.
Tang et al. <i>Journal of the National Comprehensive Cancer Network</i> , 2016 ⁽¹²⁾	Quantitative study	Terminally ill: progressive disease that does not respond to curative treatments.
Franken et al. <i>Clinical Pharmacokinetics</i> , 2016 ⁽⁹⁾	Quantitative study	Terminally ill: diagnostic survival greater than two days and less than 3 months
Franken et al. <i>European Journal of Clinical Pharmacology</i> , 2017 ⁽¹⁰⁾	Quantitative study	Terminally ill: diagnostic survival of more than two days and less than 3 months.
Tang et al. <i>Journal of Pain and Symptom Management</i> , 2016 ⁽¹³⁾	Quantitative study	Terminally ill: unresponsive to current curative treatments.
Tang et al. <i>Journal of Pain and Symptom Management</i> , 2017 ⁽¹⁴⁾	Quantitative study	Terminally ill: unresponsive to current curative treatments.
Eun et al. <i>Journal of Pain and Symptom Management</i> , 2017 ⁽³¹⁾	Qualitative study	Terminally ill: life expectancy of less than three months.
Guan et al. <i>European Neuropsychopharmacology</i> , 2014 ⁽³²⁾	Quantitative study	Terminally ill: estimated life expectancy of less than 3 months.

Peng et al. <i>American Journal of Hospice & Palliative Medicine</i> , 2014 ⁽³³⁾	Quantitative study	Terminally ill: life expectancy of less than 6 months.
Bovero et al. <i>European Journal of Cancer Care</i> , 2016 ⁽³⁴⁾	Quantitative study	Terminally ill: life expectancy up to 6 months
Modlińska et al. <i>American Journal of Hospice & Palliative Medicine</i> , 2013 ⁽³⁵⁾	Quantitative study	Terminally ill: high prevalence of fatigue, unable to work.
Seibel et al. <i>Journal of Palliative Medicine</i> , 2014 ⁽³⁶⁾	Qualitative study	Terminally ill incurable, life-threatening, progressive and advanced, with an average life expectancy of 6 months.
Huang et al. <i>PlosOne</i> , 2017 ⁽³⁷⁾	Quantitative study	Terminally ill: gastric neoplasia at clinical stage three or four.
Kwak et al. <i>Palliative Medicine</i> , 2012 ⁽³⁸⁾	Quantitative study	Terminally ill: estimated survival in less than six months.
Lloyd-Williams et al. <i>Journal of Affective Disorders</i> , 2014 ⁽³⁹⁾	Quantitative study	Terminally ill: expectation of 6 months of survival.
Ekström et al. <i>Supportive Care in Cancer</i> , 2016 ⁽⁴⁰⁾	Quantitative study	Terminally ill: advanced, incurable cancer
Ruijs et al. <i>BMC Family Practice</i> , 2013 ⁽⁴¹⁾	Quantitative study	Terminally ill: life expectancy less than 6 months.
Definitions – Palliative care		
Preissler et al. <i>BMC Palliative Care</i> , 2016 ⁽⁴²⁾	Quantitative study	Palliative care: Comprehensive care for patients with advanced incurable diseases and their families, respecting physical, psychological, social and spiritual needs. Therefore, palliative care includes medical, psychosocial, and spiritual interventions by a multiprofessional team.
Pellizzari et al. <i>Supportive Care in Cancer</i> , 2016 ⁽⁴³⁾	Quantitative study	Palliative care: Palliative care consists of a multidisciplinary team approach aimed at improving the quality of life of patients with advanced disease from the moment of diagnosis of the disease (World Health Organization, 2013). ^[3]
Bélanger et al. <i>BMC Palliative Care</i> , 2014 ⁽⁴⁴⁾	Qualitative study	Palliative care: Palliative care is a holistic and interdisciplinary approach to care that seeks to improve the quality of life of patients and their families when confronted with a life-threatening disease. It encompasses different types of decisions, such as treatment modalities for advanced cancer patients and symptom management for those suffering from terminal chronic diseases (Werth, Blevins, Chang, Sambamoorthi, 2008). ^[5]
Krakowsky et al. <i>American Journal of Hospice & Palliative Medicine</i> , 2012 ⁽⁴⁵⁾	Qualitative study	Palliative care: specialized form of health care aimed at maximizing the quality of life of terminally ill patients and helping patients and their families and friends cope with death (unreported).
Naing et al. <i>The International Medical Journal Malaysia</i> , 2016 ⁽⁴⁶⁾	Quantitative study	Palliative care: subspecialty with multidisciplinary approach to achieve quality care (without reference).

Bužgová et al. <i>Aging & Mental Health</i> , 2016 ⁽⁴⁷⁾	Quantitative study	Palliative Care: the construction of quality of life in palliative care is reported as symptom control, physical and social functioning, psychological well-being, meaning of life and social issues (Albers et al., 2010; Kaasa & Loge, 2010). ^[9]
Macartney et al. <i>Health</i> , 2014 ⁽⁴⁸⁾	Qualitative study	Palliative care: services provided by multidisciplinary teams to terminally ill patients focusing on quality of life and pain and symptom management (Palliative Care Australia, 2010).
Wallen et al. <i>Quality of Life Research</i> , 2012 ⁽⁴⁹⁾	Quantitative study	Palliative Care: individual-centered approach, concerns beyond the side effects of treatment or the progressive burden of the disease. It focuses as much on the quality of life that remains for patients as on the livelihood of their families and those close to them (Higginson, 1999).
Loggers et al. <i>Biology of Blood and Marrow Transplantation</i> , 2016 ⁽⁵⁰⁾	Quantitative study	Palliative care: specialized medical care provided by a multidisciplinary team focused on improving the quality of life of patients with severe medical conditions and their families through the alleviation of symptoms and stress of serious illness (Center to Advance Palliative Care, 2015).
Parpa et al. <i>Journal of Pain and Symptom Management</i> , 2017 ⁽⁵¹⁾	Quantitative study	Palliative care: holistic approach to care for patients with life-threatening illnesses through the treatment of physical and psychological symptoms of patients and their families, including coping with psychosocial and spiritual issues and the provision of quality of life for patients and caregivers (World Health Organization, 2017). .
Guell et al. <i>Palliative Support Care</i> , 2015 ⁽⁵²⁾	Quantitative study	Palliative care: The philosophy of palliative care is holistic. It considers physical, emotional and spiritual concerns, focusing on quality of life, relief of suffering and humanism in the doctor-patient relationship, thus dignifying the process of death (Sanz Ortiz & Bild, 1985; Foley, 1997).
Nordly et al. <i>BMC Palliative Care</i> , 2014 ⁽⁵³⁾	Quantitative study	Palliative care: approach that improves care for patients with incurable diseases and their families, including the opportunity to make their own choice of place of care and ultimately the place of death.
Seibel et al. <i>Journal of Palliative Medicine</i> , 2014 ⁽³⁶⁾	Qualitative study	Palliative care: It is an emerging policy that addresses issues such as cost effectiveness, along with economic considerations in the approach. Patients are particularly vulnerable due to physical and psychological distress, existential seizures, addictions and symptoms refractory to therapy.
Bovero et al. <i>European Journal of Cancer Care</i> , 2015 ⁽³⁴⁾	Quantitative study	Palliative care: aims to provide quality of life for patients and their families
Huang et al. <i>PlosOne</i> , 2017 ⁽⁴²⁾	Quantitative study	Palliative care: It has shared care and is for terminally ill patients who have been admitted. Such care provides biological, social, psychological, and spiritual support, and may result in changes in medical behavior, lower rates of intensive care unit admission, and fewer acute-care hospital admissions.
Definitions – End of life		
Fisher et al. <i>Journal of Pain and Symptom Management</i> , 2015 ⁽⁵⁴⁾	Quantitative study	End of life: Prognosis less than six months
Pereira & Santos. <i>European Journal of Oncology Nursing</i> , 2014 ⁽⁵⁵⁾	Quantitative study	End of life: when it is discovered that the targets set for tumor treatment should be redefined with the future goal of symptom control, when progressive malignancy is confirmed, and when death is acknowledged to be imminent and options have failed
Franken et al. <i>Clinical Pharmacokinetics</i> , 2016 ⁽⁹⁾	Quantitative study	End of life: the last hours to days before death when the patient becomes bedridden is not able to take more than sips of fluid and is no longer able to take oral medication.

Daneault et al. <i>Canadian Family Physician</i> , 2016 ⁽⁵⁶⁾	Qualitative study	End of life: remaining life expectancy of more than 12 months.
Wright et al. <i>BMJ</i> , 2014 ⁽⁵⁾	Quantitative study	End of life: last week of life.

Appendix 2. Definitions for “palliative care”, “end of life” and “terminal illness” from palliative care societies

Definitions for “palliative care”, “end of life” and “terminal illness” from palliative care societies				
Society/Country	The Economist Ranking	Palliative care	End of life	Terminal illness
The National Council for Palliative Care. United Kingdom, http://www.ncpc.org.uk/palliative-care-explained	1 st	Holistic and active care for patients with progressive and advanced disease. The management of pain and other symptoms, the provision of psychological, social and spiritual support is critical. The goal of palliative care is to achieve the best quality of life for patients and their families (NICE).	Any palliative care in the last 12 months of life is considered end-of-life care.	Not found
Palliative Care Australia. <i>Australia</i> , https://palliativecare.org.au/#	2 nd	Family and person-centered care with an active, progressive and advanced disease that has little or no prospect of cure and is expected to die, and for whom the primary goal is to optimize quality of life.	Last weeks of life for a patient with a life-limiting illness is rapidly approaching death	Not found
Fédération Bruxelloise de Soins Palliatifs et Continus. <i>Belgium</i> , https://www.fbsp-bfpz.org/soins-palliatifs-en-belgique	5 th	Continuous care and palliative care are for patients with incurable diseases and their loved ones. They aim to improve the quality of life, the treatment of pain and other symptoms, the global management of suffering by integrating the physical, psychological, spiritual and social dimensions. Continuous care and palliative care propose a coordinated network of specialized and interdisciplinary care, favoring a respectful communication of the philosophical and cultural values of the person and respect for ethical values. They are integrated into health care with the notion of continuity. Continuous care is not limited to the terminal phase but considers that the end of life is an important factor of this type of care. They consider that the end-of-life process is not a purely medical event, but a human event potentially signified by personal beliefs.	Not found	Not found
Taiwan Academy of Hospice Palliative Medicine. <i>Taiwan</i> , http://www.hospicemed.org.tw/ehc-tahpm/s/w/englishArticleList/Our_Organization	6 th	Mitigatory and supportive medical care that emphasizes the provision of total physical, psychological and spiritual care to patients and families to improve quality of life.	Not found	A disease diagnosed by a doctor as incurable in which there is medical evidence showing that the prognosis is fatal soon.
Deutsche Gesellschaft zur Palliativmedizin. <i>Germany</i> ,	7 th	There is no universally accepted equivalent to the term "palliative care" in the German language. "Palliative medicine" was initially used as a synonym for palliative care. However, the synonymous use of 'palliative medicine' and 'palliative care' has led to concerns about the	Period from one to two years, during which the patient, family and	Not found

https://www.dgpalliativmedizin.de/images/DGP_GLOSSAR.pdf		medicalization of palliative care in Germany. Therefore, some experts use the English term “palliative care” to distinguish it from "palliative medicine".	professional realize that the disease has become advanced and life-limiting. In contrast, end-of-life care can be understood more specifically as patient care in the last hours or days of life. Due to the ambiguity of the term definition, the German Society of Palliative Medicine advises, for a precise description of the context, the term care in the “dying process”.	
Integral Kankercentrum Nederland. <i>Netherlands</i> , https://www.pallialine.nl/richtlijn/item/index.php?pagina=/richtlijn/item/pagina.php&richtlijn_id=1018	8 th	Multidimensional care in which quality of life is central. Attention is focused on the physical, psychological, social and existential dimensions. In principle, this care is offered in a multidisciplinary way. The focus is not only on those who are sick and die, but also on their loved ones, during illness and after the person has died. In the treatment and care plan, the individual goals, needs, limits and desires of the patient are considered.	Not found	Not found
National Hospice and Palliative Care Organization. <i>United States of America</i> , https://www.nhpco.org/	9 th	Patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care, throughout the disease process, involves meeting physical, intellectual, emotional, social and spiritual needs and facilitating patient autonomy, access to information and choice.	Not found	Not found
Société Française d’Accompagnement et des Soins Palliatifs. <i>France</i> , http://www.sfap.org/rubrique/definition-et-organisation-des-soins-palliatifs-en-france	10 th	Palliative care provided from a comprehensive approach to the person with a serious, progressive or terminal illness. The purpose of palliative care is to relieve physical pain and other symptoms, but also to intervene in psychological, social and spiritual suffering. Palliative care and follow-up are interdisciplinary. They address the person considered as a person, their family and their close people, at home or in institutions.	End-of-life situations include especially people who have a severe, progressive, advanced, potentially deadly disease or with a short to medium-term life expectancy.	Progressive and potentially deadly disease.
Canadian Hospice Palliative Care Association. <i>Canada</i> , http://www.chpca.net/	11 th	They are appropriate for anyone and/or family living or at risk of developing a life-threatening disease due to any diagnosis, with any prognosis, regardless of age and at any time who have unmet needs and/or needs. and are prepared to accept care. They can complement and improve disease-modifying therapy, or they can become the full focus of care.	Not found	Not found
Singapore Hospice Council. <i>Singapore</i> , https://singaporehospice.org.sg/palliativcare/	12 th	Palliative care aims to alleviate suffering and improve the quality of life of patients and their families, taking care of the whole person, physically, emotionally, psychologically and spiritually. Palliative care seeks to support the patient throughout the treatment.	Not found	Not found
Japanese Society for Palliative Medicine. <i>Japan</i> , https://www.jspm.ne.jp/jspm_eng/	14 th	Care provided in cooperation with medical and social care professionals who seek to improve the quality of life of patients with life-threatening and difficult-to-cure diseases and their families. Palliative care is provided so that patients and their families can live in the most dignified and comfortable way possible.	Not found	Not found

Société Suisse de Médecine et de Soins Palliatifs. <i>Switzerland</i> , http://www.palliative.ch/fr/soins-palliatifs/en-quoi-consistent-les-soins-palliatifs/	15 th	They include medical support and treatment for people suffering from incurable, potentially deadly and/or chronic evolutionary diseases. Although they are introduced at an early stage, they intervene mainly at a time when diagnosis is or appears to be compromised and where curative care is no longer the primary goal. They offer patients, given their situations, the best quality of life until their deaths by providing adequate support to their families. Palliative care aims to avoid suffering and complications. They comprise medical treatments, care as well as psychological, social and spiritual support. Palliative care should consider the patient in its entirety. It is about anticipating and mitigating symptoms and suffering as best as possible.	We cannot define the exact moment when the last phase of life begins. It can last hours, days, weeks, even months. Patients' activities become increasingly restricted despite adequate treatment of symptoms.	Not found
Korean Society for Hospice and palliative care society. <i>South Korea</i> , http://www.hospicecare.or.kr/	18 th	Palliative care aims to improve quality of life by relieving pain and physical, psychological, social and spiritual suffering in terminally ill patients and their families.	Not found	Not found
Hong Kong Society of Palliative Medicine. <i>Hong Kong</i> , https://www.hkspm.com.hk/	22 nd	It adopts the concept of the World Health Organization.	Not found	Not found
The Israeli Association of Palliative Care. <i>Israel</i> , http://www.palliative.org.il/tmicha-the-israeli-association-of-palliative-care/	25 th	Palliative care is the most appropriate treatment for patients with severe and incurable diseases, as it is a therapeutic approach that improves the quality of life of patients and their families by dealing with incurable diseases at any age, preventing and alleviating suffering by identifying and careful assessment of symptoms, pain and other problems: physical, mental and spiritual. Palliative care not only improves the quality of care, but also emphasizes the importance of continuity of care and saves unnecessary costs on the health system by preventing frequent visits to the emergency room, frequent hospitalization and unnecessary treatment.	Not found	Not found
Sociedad Chilena de Medicina Paliativa. <i>Chile</i> , http://www.sochimedpal.cl/index.html	27 th	It adopts the concept of the World Health Organization.	Not found	Life forecast six months or less
Mongolian Palliative Care Society. <i>Mongolia</i> , https://www.facebook.com/Mongolian-Palliative-Care-Society-366258126836809/	28 th	Not found	Not found	Not found
Asociación Costarricense de Medicina Paliativa y Medicina del Dolor. <i>Costa Rica</i> , https://www.facebook.com/asocmepd/	29 th	Not found	Not found	Not found
Asociación Panameña de Cuidados Paliativos. <i>Panamá</i> , https://www.paho.org	31 st	Appropriate care for the patient with advanced and progressive disease, where control of pain and other symptoms, as well as psychosocial and spiritual aspects, become more important. The goal is to achieve the best quality of life possible for the patient and their family.	Preceding period, when severe physical deterioration, extreme weakness, high frequency of cognitive and conscious disorders, relationship or	Not found

			ingestion difficulty, and life prognosis in hours or days occur gradually.	
Asociación Argentina de Medicina y Cuidados Paliativos. <i>Argentina</i> , https://aamycp.com.ar	32 th	Care for people with advanced disease and their families when medical expectation is not the cure. The main goal is to improve the quality of life of patients and their families by providing comprehensive care provided by interdisciplinary work teams.	Not found	Not found
Hospice Palliative Care Association of South Africa. South Africa,	34 th	It adopts the concept of the World Health Organization.	Not found	Not found
Palliative Care Association of Uganda. <i>Uganda</i> , https://pcauganda.org/	35 th	It adopts the concept of the World Health Organization.	Not found	Not found
Palliative Care Malaysia. <i>Malaysia</i> , https://www.facebook.com/PalliativeMY/	38 th	It adopts the concept of WHO and WPCA.	Not found	Not found
Sociedad Ecuatoriana de Cuidados Paliativos. <i>Ecuador</i> , https://www.facebook.com/AsociacionPaliativosEcuador/	40 th	Not found	Not found	Not found
Academia Nacional de Cuidados Paliativos. <i>Brazil</i> , https://paliativo.org.br/	42 th	Adopts the WHO concept	Not found	Not found