

Knowledge of patients with cancer about palliative care: a bibliometric study

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Abstract

This research seeks to characterize the bibliometric indicators regarding cancer patients's knowledge about palliative care. Bibliographic search associating the descriptors "patient," "palliative care," "knowledge" and "neoplasm" found low publication ratio and limited connexion among authors. Asian countries account for most publications, but the level of knowledge on the topic was limited given its strong association with end-of-life care aimed at hospitalized cancer patients without possibility of cure. Mapping the main bibliometric indicators on knowledge about palliative care pointed out the need for further publications on the topic to provide better understanding.

Keywords: Palliative care. Knowledge. Elderly. Neoplasms.

Resumo

Conhecimento de pacientes com câncer sobre cuidados paliativos: estudo bibliométrico

Esta pesquisa busca caracterizar os indicadores bibliométricos acerca do conhecimento de pacientes com câncer sobre cuidados paliativos. Por meio da associação dos descritores "patient", "palliative care", "knowledge" e "neoplasm" encontrou-se baixa taxa de publicação, com tendência a elevação, além de rede de conexão limitada entre os autores. Os países asiáticos foram os que mais publicaram, mas observou-se nível de conhecimento limitado sobre o tema, pois há forte associação com cuidados de fim de vida, destinados apenas a pacientes com câncer, internados em hospital e sem cura. Este estudo permitiu mapear os principais indicadores bibliométricos a respeito do conhecimento de pacientes com câncer sobre os cuidados paliativos, sendo perceptível o crescimento de publicações sobre o tema, mas ainda com baixa quantidade total. Evidencia-se, assim, a necessidade de mais publicações para a obtenção de maior entendimento sobre o tema.

Palavras-chave: Cuidados paliativos. Conhecimento. Idoso. Neoplasias.

Resumen

Conocimiento de los pacientes con cáncer sobre cuidados paliativos: un estudio bibliométrico

Este estudio tiene como objetivo caracterizar los indicadores bibliométricos de conocimiento de los pacientes con cáncer sobre cuidados paliativos. A partir de la asociación entre las palabras clave "patient", "palliative care", "knowledge" y "neoplasm", se constató una baja tasa de publicación, con tendencia al alza, así como una limitada red de conexiones entre autores. Los países asiáticos fueron los que más publicaron, aunque el nivel de conocimientos sobre el tema era limitado, ya que lo asocian a los cuidados al final de la vida, destinados únicamente a los pacientes oncológicos, hospitalizados y no curados. Este estudio permitió trazar los principales indicadores bibliométricos sobre el conocimiento de los cuidados paliativos por parte de los pacientes con cáncer, y se observó que hubo un aumento de las publicaciones sobre el tema, aunque el número total sigue siendo bajo. Esto pone de manifiesto la necesidad de más publicaciones para conocer mejor el tema.

Palabras clave: Cuidados paliativos. Conocimiento. Anciano. Neoplasias.

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A process of demographic transition is underway throughout the world. In developing countries, this is occurring at an accelerated rate, causing an increase in life expectancy. It is estimated that older adults will account for 33% of the Brazilian population in 2060, up from 7.6% in 2020¹⁻³. Aging is influenced by several factors and characterized by a greater susceptibility to chronic diseases, including cancer⁴, whose number of cases is expected to double between 2015 and 2035⁵.

Patients with cancer and their families undergo intense suffering, not only in physical terms but also in social loss and psychological and spiritual suffering, especially when the disease is advanced⁶. One of the strategies validated and recommended by guidelines is to associate palliative care with the regular care of cancer patients, especially when the disease is in an advanced stage, alongside curative or disease-modifying therapy⁷.

The discussion about palliative care as a practice that changes patients' reality, bringing benefits to them and their families, has been ongoing since the 1960s, with the modern hospice movement. Palliative care is provided by a specialized multidisciplinary team, in tandem with standard treatment, providing patients with comprehensive support. Such care goes beyond treating the disease, supporting patients and family members in their physical, psychological, social and spiritual needs, in addition to providing care planning focused on reducing symptoms and increasing the quality of life^{7,8}.

Despite the proven benefits, the implementation of palliative care faces several barriers. Since 2014, the Worldwide Hospice Palliative Care Alliance has highlighted the importance of spreading knowledge of this specialty among healthcare providers, patients and families,⁹ since poor or mistaken knowledge may hinder the implementation of this type of care¹⁰.

In recent decades, the number of publications on palliative care has increased, which shows its importance and the growing interest of researchers on the topic. The studies are mainly dedicated to evaluating the knowledge of caregivers and healthcare providers about palliative care in the oncology area. However, few studies address the knowledge of cancer patients on the topic¹¹.

In view of the above, this study proposed the following guiding question: What are the bibliometric indicators of scientific production available in online journals regarding the knowledge of cancer patients about palliative care? In order to answer it, the study aims to characterize such indicators.

Method

This is a bibliometric study, a method that makes it possible to map the literature in an objective manner by using bibliometric indicators in order to answer questions about the impact of research on society and measure the patterns of scientific production and their trends over time¹². The productivity of the identified journals is evaluated by using Bradford's law, a mathematical analysis that makes it possible to group journals into zones, considering individual productivity¹³.

The study began in October 2022, with searches in Scopus and Web of Science, the most comprehensive and multidisciplinary databases used in this type of review, covering literature in the field of biomedical science. Scopus also covers 100% of the MEDLINE database material. The search strategy for this review is based on the association of the descriptors "patient," "palliative care," "knowledge" and "neoplasm," with singular and plural synonyms, to make the search as comprehensive as possible, with the Boolean operator "and."

Full articles published in online journals about cancer patients' knowledge regarding palliative care were included in the sample. Newsletters, editorials, brief communications and book chapters were excluded. The search covered all publications available in the databases, regardless of time period or language.

The article screening process was carried out using the preferred reporting items for systematic reviews and meta-analyses (PRISMA) methodology. All the basic information of the collected articles – author, title, abstract, keyword, journal, year of publication, authors' affiliation, number of citations and impact factor—were downloaded from the Web of Science and Scopus database and organized in an Excel spreadsheet. Duplicate

articles were excluded and, after reading and analysis by two independent authors, studies that did not meet the inclusion criteria were excluded.

The data from the included articles were imported into BiblioShiny (bibliometrix package in R 4.2.0) to automatically analyze bibliographic information. The information included global publication trends, global citation trends, country/institution/journal distributions, historical direct citation network, thematic map of author keywords, international collaborations, most cited journals/articles/references locally and most cited articles globally. All figures and tables were exported directly from BiblioShiny.

Bradford's law was used to evaluate the distribution of articles in scientific journals, making it possible to separate the total number of journals into groups or zones, determined by individual productivity. In the zones are the journals that publish less frequently; in the core those with the highest productivity.

Results

The methodology used for the study found 126 articles on Web of Science (70) and Scopus (56). During the screening and pre-analysis process, 80 were excluded for being duplicates, and following the reading of title, abstract and full text, another 33 articles that did not correspond to the research objective were excluded. Eventually, 13 documents, published between 2012 and 2022, were subjected to analysis.

The first study selected is from 2012 and no publications were identified in the following year. There was an isolated increase in 2018 and an upward trend in 2021 and 2022, with two publications in each year.

Some heterogeneity was observed (Table 1) regarding the number of publications by country of the institutions to which the main authors are affiliated, with Singapore, Australia and South Korea having two publications each. Together, they account for approximately 45% of publications, while the other countries have one publication each. Next are featured data related to the main institutions to which the authors are affiliated, also with a heterogeneous distribution, without major differences. Duke-NUS Medical School and Seoul National University Hospital rank first with two publications each and the other institutions have one publication each.

Table 2 features the most relevant articles and journals, classified by the total number of citations. The top ranked¹⁴ has 193 citations, almost four times more than the second,¹⁵ even though it was published in the *Canadian Medical Association Journal*, which is located in zone 3 of the Bradford distribution, with an impact factor of 16.9. The subsequent three articles in the top ten globally cited list were published in higher impact factor journals, located in Bradford zone 1. The journal with the best position in the Bradford zones (*Journal of Symptom and Pain Management*), with a very high impact factor (5.575), did not have any articles among the most cited, possibly because they were published more recently (2021 and 2022).

Table 1. Number of articles by country and institution of origin of the authors' affiliation.

Country	Number of Articles	Percentage
Singapore	2	15%
Australia	2	15%
South Korea	2	15%
Brazil	1	7%
U.S.	1	7%
Canada	1	7%
India	1	7%

continues...



Table 1. Continuation

Country	Number of Articles	Percentage
Iran	1	7%
Japan	1	7%
Ethiopia	1	7%
Total	13	100%
Institution	Number of Articles	Percentage
Duke-NUS Medical School	2	18%
Seul National University Hospital	2	18%
Universidade Federal de Alagoas	1	9%
University of Toronto	1	9%
University of Pennsylvania	1	9%
Shahid Sadoughi University of Medical Science	1	9%
Monash University	1	9%
St. Vicent Public Hospital Melbourne	1	9%
Arba Minch College of Health Science	1	9%
Dr. B. R. A. Institute-Rotary Cancer Hospital	1	9%
Other	1	9%
Total	13	100%

Table 2. Most relevant articles and journals by number of citations

Articles	Year of publication	Journal	Total citations
“Perceptions of palliative care among patients with advanced cancer and their caregivers” ¹⁴	2016	<i>Canadian Medical Association Journal</i>	193
“Initial perceptions of palliative care: an exploratory qualitative study of patients with advanced cancer and their family caregivers” ¹⁵	2017	<i>Palliative Medicine</i>	48
“Knowledge beliefs and concerns about opioids, palliative care and homecare of advanced cancer patients: a nationwide survey in Japan” ¹⁶	2012	<i>Supportive Care in Cancer</i>	20
“Terminal cancer patients’ and their primary caregivers’ attitudes toward hospice/palliative care and their effects on actual utilization a prospective cohort study” ¹⁷	2014	<i>Palliative Medicine</i>	16
“Assessment of knowledge accessibility and utilization of palliative care services among adult cancer patients at Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia, 2014: a cross-sectional institution based study palliative care” ¹⁸	2015	<i>BMC Research Notes</i>	12
“Attitudes toward early palliative care in cancer patients and caregivers: a Korean nationwide survey” ¹⁹	2018	<i>Cancer Medicine</i>	10
“Cancer patients’ perceptions of palliative care” ²⁰	2020	<i>Supportive Care in Cancer</i>	8
“Palliative care awareness among advanced cancer patients and their family caregivers in Singapore” ²¹	2019	<i>Annals of the Academy of Medicine, Singapore</i>	4

continues...

Table 2. Continuation

Articles	Year of publication	Journal	Total citations
"Initial perceptions about palliative care in patients with advanced cancer: a prospective cross-sectional audit" ²²	2018	<i>Indian Journal of Palliative Medicine</i>	2
"The level of knowledge about palliative care in Iranian patients with cancer" ²³	2022	<i>BMC Palliative Care</i>	1

When analyzing the journals according to Bradford's law (Table 3), the *Journal of Pain and Symptom Management* appears in zone 1, the most central, followed by *Palliative Medicine* and *Supportive Care in Cancer*, all with a high impact factor. *Cancer Medicine* and *BMC Palliative Care*—zones 3 and 2, respectively—have few individual publications, despite the high impact factor in the production of this specific subject.

In the study proposed, the selected articles were identified by using common keywords specified by the authors to summarize the focus of their work. Thus, when analyzing the occurrence of these keywords in a word cloud, the terms "cancer" and "patient" stand out. The most frequent words in the abstracts were also evaluated, with "care," "patient," "palliative" and "cancer" being the most repeated.

Table 3. Distribution of journals in productivity zones

Journal	Impact factor	Ranking	Frequency	Zone
<i>Journal of Pain and Symptom Management</i>	5.576	1	2	1
<i>Palliative Medicine</i>	5.713	2	2	1
<i>Supportive Care in Cancer</i>	3.359	3	2	1
<i>Annals of the Academy of Medicine, Singapore</i>	0.514	4	1	2
<i>BMC Palliative Care</i>	3.113	5	1	2
<i>BMC Research Notes</i>	0.527	6	1	2
<i>Cancer Medicine</i>	4.711	7	1	3
<i>Canadian Medical Association Journal</i>	16.9	8	1	3
<i>Indian Journal of Palliative Medicine</i>	0.949	9	1	3
<i>Revista Bioética</i>	-	10	1	3

The study population consisted of adult cancer patients, and five of the articles also evaluated family members and/or caregivers. Regarding methodology, two studies are qualitative (15.3%) and used semi-structured interviews to collect empirical material, two studies (15.3%) used mixed approaches and the others (69.2%) adopted a quantitative approach. Only two articles used a questionnaire previously validated in the literature; the others administered non-validated questionnaires, mostly designed by the actual author, or semi-structured interviews.

Discussion

A small number of articles were found in the databases selected to search for the investigated subject. The first article was published in 2012. However, despite an increase over the years, especially in 2018, 2021 and 2022, with two publications in each year, the average production rate was 1.18 articles per year.

This is corroborated by a scoping review published in 2021, which aimed to characterize publications

about palliative care and communication. Eighty-six publications were identified between 2014 and 2018, showing a gradual increase, with a peak in 2017 and 2018¹¹. The growth seems to be related to several variables, including the recognition of palliative care as a specialty and the greater identification of palliative needs.

In relation to the distribution of articles based on country and institutional affiliation of the main author, an important heterogeneity was identified. The 13 articles are distributed across ten countries and eleven institutions, with a large representation from the Asian continent, accounting for 53.8%, and no representatives from the European continent. These data go against a bibliometric study that mapped and analyzed global publication trends on palliative care, according to which the United States and the United Kingdom were the countries with the highest number of publications and citations²⁴.

A report published by *The Economist* magazine²⁵ on quality of death evaluates the care provided to terminal patients in different countries, considering the availability of human and material resources, in addition to their form of organization. The study ranks the countries, making it possible to compare them with the countries of the institutions to which the main author is affiliated in this study. Among the ten top ranked countries are South Korea and Australia, in 4th. Next come Canada in 22nd, Singapore in 23rd and Japan in 24th. Iran is the only country not mentioned in the report.

A study published in *Health* magazine in 2015 emphasizes the quality of palliative care provided in South Korea, highlighting the development process and the government efforts made to implement a public policy on the subject from 2004²⁶. Australia, in turn, has had government initiatives since 2000 and is recognized for its excellence in palliative care²⁷.

The impact factor, a key piece of data regarding the relevance of scientific journals, is determined from the average number of citations over a given time span: the higher the impact factor, the more relevant the journal²⁸. The author who published the most on the subject, "Lee J," was published in a journal with a high impact factor, which points to the relevance of the subject. However, the articles had a low number of citations, with one of them having no citations in the databases.

Networking among the actors is fairly limited, showing low local and global cooperation and the formation of isolated subgroups. This pattern is also noticeable in other studies, such as a bibliometric review that mapped publications on palliative care between 2002 and 2020, showing low international cooperation²⁸.

When analyzing the methodology of the studies, a prevalence of quantitative approaches is observed, aiming at an objective analysis of knowledge about palliative care. Only two articles used a previously validated questionnaire—the only one found in the study²⁹—the Palliative Care Knowledge Scale (PaCKS). This instrument, developed and published in 2017 in *Palliative and Supportive Care*, consists of the analysis of 13 items with true or false answers and has been used in several studies. It was administered to assess knowledge about palliative care in Iranian patients²³, Bangladeshi physicians³⁰ and individuals from Australia³¹, which attests to its reproducibility and validity in different contexts.

Regarding the way in which the knowledge of cancer patients about palliative care is measured in quantitative studies, there is not much standardization. Except for the articles that used the PaCKS questionnaire, there was no definition of the meaning of knowledge about palliative care, based on the proposed instruments. Although the quantitative studies attempted to make the analysis of knowledge on the topic more objective, they presented a better characterization of understanding when evaluating patients' statements, for example.

Regardless of the method chosen, there is homogeneity in the outcomes: it is concluded that most cancer patients had low to moderate knowledge about palliative care^{20,22,23,32,33}, closely associated with end-of-life care, impossibility of cure and exclusive care for hospitalized patients and cancer patients^{14,16,22,33}.

This finding corroborates previously published reviews, such as the one carried out by Masoud, Imane and Naiire³⁴, a systemic review on patients' knowledge about palliative care that included articles published from 2000 to 2021. This study showed that more than half of patients have no knowledge of this approach and mistakenly associate it with end-of-life care.

Final considerations

The data obtained in this bibliometric study made it possible to map the main indicators of the investigated articles on the knowledge of cancer patients about palliative care. The growing interest in the subject in recent years was evident, especially in South Korea, Singapore and Australia.

Despite the exponential growth in publications about palliative care, studies on the knowledge

of cancer patients are still scarce. This reveals the need to better understand the gaps that exist in this context, creating opportunities to carry out studies that enable more in-depth discussion.

This study has several limitations, such as the search for original articles in the Scopus and Web of Science databases. The search was carried out using specific keywords found in titles and abstracts, so it may not have included all published articles.

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Cláudio Emmanuel Gonçalves da Silva Filho designed the scientific project and contributed to the methodology, results, writing, discussion and conclusions. Solange Fátima Geraldo da Costa contributed to the methodology, discussion and review. Lucas do Nascimento Barbosa, Cláudia Batista Mélo and Carmen Sílvia Laureano Dalle Piage contributed to the methodology and analysis of results. Maria Adelaide Silva Paredes contributed to the scientific project, methodology, results, discussion and review.

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