Caregivers' understanding of palliative care offered to their family members

A compreensão dos cuidadores sobre os cuidados paliativos ofertados aos seus familiares

Comprensión de los cuidadores sobre los cuidados paliativos ofrecidos a sus familiares

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REVIEW

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RESUMO

Objetivo: analisar a produção do conhecimento sobre a compreensão dos cuidadores sobre o conceito de cuidados paliativos no período de 2019 a 2023. **Método:** Realizou-se uma revisão de escopo utilizando as plataformas PUBMED, COCHRANE, BVS e SCIELO entre julho e outubro de 2023. A amostra final incluiu 5 artigos. **Resultados**: Os estudos revelaram uma lacuna no conhecimento dos cuidadores sobre o conceito de cuidados paliativos, tanto em âmbito nacional quanto internacional. Também destacaram o impacto do conhecimento sobre cuidados paliativos na qualidade do cuidado oferecido ao paciente. **Conclusão:** Novas pesquisas são necessárias para elucidar como a compreensão dos cuidados paliativos é formada tanto pelos cuidadores quanto pelos pacientes, a fim de contribuir para melhores práticas de cuidado, além de fomentar políticas públicas mais eficazes nesta área.

Descritores: Cuidadores; Cuidados paliativos; Compreensão.

ABSTRACT

Objective: to analyze the production of knowledge on caregivers' understanding of the concept of palliative care from 2019 to 2023. **Method:** A scoping review was carried out using the PUBMED, COCHRANE, BVS e SCIELO platforms between July and October 2023. The final sample included 5 articles. **Results:** The studies revealed a gap in caregivers' knowledge about the concept of palliative care, both nationally and internationally. They also highlighted the impact of knowledge about palliative care on the quality of care offered to patients. **Conclusion:** further research is needed to elucidate how the understanding of palliative care is formed by both caregivers and patients, to contribute to better care practices, as well as to foster more effective public policies in this area.

Descriptors: Caregivers; Palliative care; Comprehension.

RESUMEN

Objetivo: analizar la producción del conocimiento sobre la comprensión de los cuidadores sobre el concepto de cuidados paliativos en el período de 2019 a 2023. **Método:** se realizo una revisión de Escopo utilizando las plataformas PUBMED, COCHRANE, BVS y SCIELO entre julio y octubre de 2023. Una muestra final que incluye 5 artículos. **Resultados:** os estudos revelam uma lacuna no conhecimento dos cuidadores sobre o conceito de cuidados paliativos, tanto em âmbito nacional quanto internacional. Também destacaram o impacto do conhecimento sobre cuidados paliativos na qualidade do cuidado oferecido al paciente. **Conclusión:** Nuevas investigaciones son necesarias para dilucidar cómo comprender dos cuidados paliativos y están formadas tanto por pelos cuidadores como por pelos pacientes, a fin de contribuir para mejores prácticas de cuidado, además de fomentar políticas públicas más eficaces en esta área.

Descriptores: Cuidadores; Cuidados paliativos; Comprensión

Introduction

Palliative care can be defined as an important approach to prevent and alleviate the suffering of adults, adolescents and children with life-threatening diseases[1]. The goal is to identify and control suffering in its physical, psychological, social, and spiritual aspects. To this end, it is necessary to apply measures early and integrate them into treatments that modify the disease, from the diagnosis of a serious disease. The intent is not to hasten death or limit treatments, but rather to provide comfort and align the treatment of the disease with the values and beliefs of the patient and his family [2.3].

Palliative care requires the involvement of a multidisciplinary group and is associated with the patient's overarching needs, extending beyond the scope of their diagnosis. The goal is to provide comprehensive care to the sick individual as well as their family with the aim of mitigating human suffering [4].

The palliative approach should not be limited to the patient alone, but also extend to family members, ensuring ongoing support throughout the course of the illness and during the grieving period, as well as their involvement in decision-making about care. In addition, it is critical to provide ongoing guidance on the progression of the life-threatening disease, as well as to assess the family caregiver's understanding of this information. [5]

A family caregiver is defined as someone within the patient's direct social network, such as a spouse, adult child, sibling, nephew, parent, or who provides help, protection, or assistance with daily activities. These caregivers, often unpaid, may not possess the appropriate knowledge or training to address the patient's needs, which vary in intensity and duration[6]. Family care can encompass a variety of settings, including serious, incurable illnesses, long-term mental health problems, or disabilities [7].

The literature consistently highlights the importance of effective communication between the multidisciplinary palliative care team and the patient-family or patient-caregiver binomial aiming at a better understanding of treatment and decision-making [8. 9.10.]

Although some international studies collectively interpret the degree of awareness about palliative care as suboptimal, these studies took place more than a decade ago.[11.12.13] In this way, the possibility arises to investigate and understand the caregivers' understanding of what palliative care is offered to their relatives.

Thus, the objective of this study is to analyze the production of knowledge about caregivers' understanding of the concept of palliative care in the period from 2019 to 2023.

Method

This is a scoping review study, based on the assumptions of the review method presented by the Joanna Briggs Institute (JBI) 14, which can be used to explore, expand, structure and clarify the main evidence that provides support for a given field of research. The scoping review was considered, as it aims to elucidate the main concepts and definitions existing in the literature, in addition to identifying related characteristics or factors, aiming to analyze the gaps in existing knowledge within that theme.

Five stages of investigation were adopted: (1) identify the research question; (2) locate relevant studies; (3) select studies; (4) extract data; and (5) collect, summarize, and report the results.[14]

To elaborate the research question, the PCC mnemonic strategy was used, where P = population, C = concept and C = context. In this review, the terms were indicated as follows: Population: caregivers; Concept: Understanding and Context: palliative care. After using the strategy described, it was possible to elaborate the following guiding question: Do caregivers (Population) understand (Concept) what palliative care (Context) is offered to their relatives?

The search for studies took place from July to October 2023 using the following databases: PUBMED (National Library of Medicine), VHL (Virtual Health Library), Cochrane (Cochrane Database of Systematic Reviews) and Scielo (Scientific Electronic Library Online). The terminology used for the search was based on the Medical Subject Headings (MESH) and the Health Sciences Descriptors (DECS). A search strategy was developed using previously identified descriptors (Caregivers, Comprehension, Palliative Care), as well as their respective synonyms. To construct the search strategy, the acronym PCC was used, being P: population (caregivers), C: concept (understanding) and C: context (palliative care). Chart 1 exemplifies the search strategy adopted:

Chart 1 - Search strategy for scope review. 2024.

Database used	Search strategy
PUBMED (455 estudos)	"Caregivers"[Mesh] or (Caregiver) or (Carers) or (Carer) or (Care Givers) or (Care Giver) or (Spouse Caregivers) or (Caregiver, Spouse) or (Caregivers, Spouse) or (Spouse Caregiver) or (Family Caregivers) or (Caregiver, Family) or (Caregivers, Family) or (Family Caregiver) or (Informal Caregivers) or (Caregiver, Informal) or (Caregivers, Informal) or (Informal Caregiver) AND "Comprehension"[Mesh]or(Understanding)or(Readabil ity) AND "Palliative Care"[Mesh] or (Care, Palliative) or (Palliative Treatment) or (Palliative Treatments) or (Treatment, Palliative) or (Treatments, Palliative) or (Therapy, Palliative) or (Palliative Therapy) or (Palliative Supportive Care) or (Supportive Care, Palliative) or (Palliative Surgery) or (Surgery, Palliative).
BVS (LILACS, BDENF, MEDLINE, COLETÂNIA SUS, INDEX PSICOLOGIA, SEC EST SAÚDE SP (17 estudos)	"Cuidadores" or (Cuidador) or (Cuidador Familiar) or (Cuidador de Família) or (Cuidadores Cônjuges) or (Cuidadores Familiares) or (Cuidadores Informais) or (Cuidadores de Família) or (Cônjuges Cuidadores) or (Familiar Cuidador) or (Familiares Cuidadores) or (Outro Apoiador) AND "Compreensão" or (Compreensibilidade) or (Compreensão de Leitura) or (Entendimento) or (Legibilidade) AND "Cuidados Paliativos" or (Assistência Paliativa) or (Cuidado Paliativo) or (Cuidado Paliativo de Apoio) or (Tratamento Paliativo)

COCHRANE (43 estudos)	(Caregivers) or (Caregiver) or (Carers) or (Carer) or (Care Givers) or (Care Giver) or (Spouse Caregivers) or (Caregiver, Spouse) or (Caregivers, Spouse) or (Spouse Caregiver) or (Family Caregivers) or (Caregiver, Family) or (Caregivers, Family) or (Family Caregiver) or (Informal Caregivers) or (Caregiver, Informal) or (Caregivers, Informal) or (Informal Caregiver) AND (Comprehension) or (Understanding) or (Readability) AND (Palliative Care) or (Care, Palliative) or (Palliative Treatment) or (Palliative Treatments) or (Treatment, Palliative) or (Treatments, Palliative) or (Therapy, Palliative) or (Palliative Therapy) or (Palliative Supportive Care) or (Supportive Care, Palliative) or (Palliative Surgery) or (Surgery, Palliative)
SCIELO (1 estudo)	("Cuidadores" or (Cuidador) or (Cuidador Familiar) or (Cuidador de Família) or (Cuidadores Cônjuges) or (Cuidadores Familiares) or (Cuidadores Informais) or (Cuidadores de Família) or (Cônjuges Cuidadores) or (Familiar Cuidador) or (Familiares Cuidadores) or (Outro Apoiador)) AND ("Compreensão" or (Compreensibilidade) or (Compreensão de Leitura) or (Entendimento) or (Legibilidade)) AND ("Cuidados Paliativos" or (Assistência Paliativa) or (Cuidado Paliativo) or (Cuidado Paliativo de Apoio) or (Tratamento Paliativo))

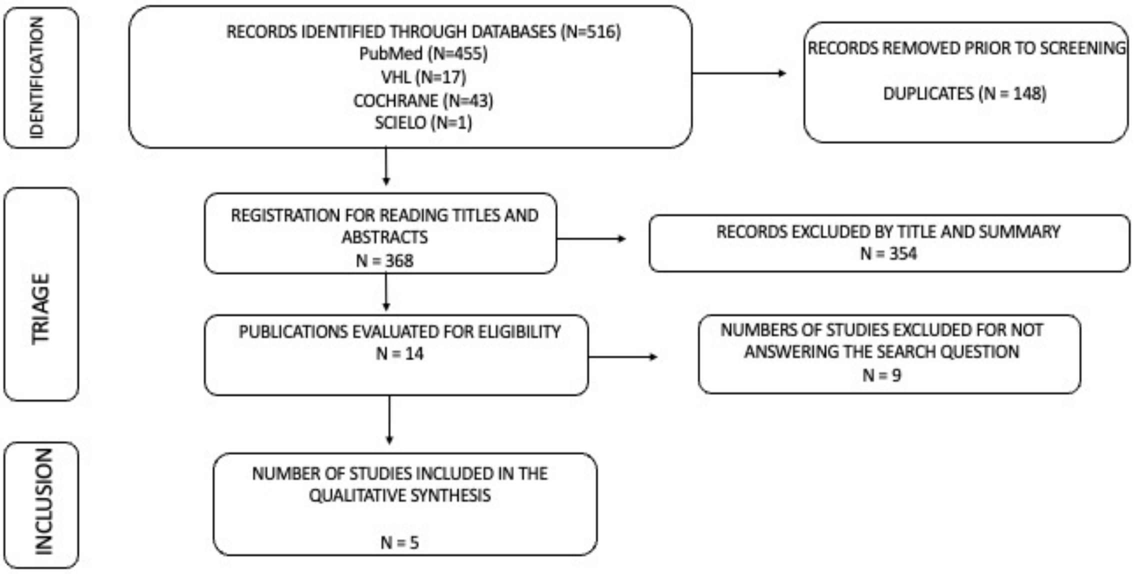
The inclusion criteria were publications from 2019 to 2023, complete articles available for access on the CAPES journal portal, productions in English, Spanish and Portuguese, empirical studies and that presented contextualization regarding the investigated subject.

Duplicate articles that did not meet the inclusion criteria were excluded, as well as review articles, opinion articles, editorials, theses, and dissertations. The selection of studies was initially carried out by reading the titles and abstracts, based on the inclusion criteria, totaling 516 articles, of which 14 publications were considered potentially eligible and selected for full reading, of which 5 were included in the final sample of this integrative review, as they clearly answered the research question of the present review.

The selection of studies was carried out by two independent reviewers, and any discrepancies were resolved by a third evaluator. The titles and abstracts of the references identified through the search strategy were evaluated, and potentially eligible studies were pre-selected. In this stage of the review, the systematic review and screening management software called Rayyan-Intelligent Systematic Review - RAYYAN SYSTEMS INC, 2021, was used to enable the selection and analysis of studies retrieved from the databases 15. Soon after, the full text of the pre-selected studies was read to confirm eligibility.

Figure 1 shows the process of searching, excluding and including the selected articles, according to the recommendations of PRISMA-ScR.[16]

Figure 1 - Selection flow of review articles, according to PRISMA. Rio de Janeiro, Brazil, 2020. 17.



Results

The search strategy retrieved 516 studies. During the screening process, 148 duplicate references (identical references) and 354 that did not meet the research question after reading the title and abstract were eliminated.

From the reading of the full text of the 14 selected references, 9 did not answer the research question and 5 were included in the qualitative synthesis.

The synthesis of the articles was grouped in Chart 2, referring to the characterization by title, year, place, base, objectives, study method, participants, and contributions. The 5 articles included in this review were published in 2019(1), 2020(2) and 2021(2).

Table 2 - Knowledge and Perceptions about palliative care, 2024.

Title/Author	Year/Location /Base	Objectives	Methodology/ Participants	Conclusions
1. Social representations of family members of pediatric patients who are not currently available for treatment [18]	2019 Brazil Rev.Pesqui. Cuid.Fundam	To describe the caregivers' understanding of pediatric FPTA clients about cancer and its repercussions for home care	This is a descriptive research, with the use of a qualitative approach employing the theory of social representations. N = 10 family members of cancer patients	- - Caregivers understand the pathology that affects their patient; - - Caregivers assimilate the guidelines employed by the multidisciplinary palliative care team for terminal cancer patients; The association of these factors is fundamental in the provision of -of care.

2. Perceptions, knowledge and attitudes towards the concept and approach of palliative care amongst caregivers: a cross-sectional survey in Karachi, Pakistan[6]	2020 Pakistan BMC Paliative Care	Determine knowledge, in terms of caregivers' perceptions and attitudes, about the concept and principles of palliative care.	Cross-sectional study/ N = 250 caregivers	- Almost half of the caregivers had a partial understanding of the holistic approach to palliative care. They demonstrate an understanding of two key aspects: that health care should be offered to all suffering from life-threatening illnesses, and that this approach encompasses Not only physical needs, but also psychological and social ones. - It has been established by the WHO and repeatedly observed in the literature that knowledge deficits and Misunderstandings are among the main challenges in providing care Palliative.
3.Experiences of Caregivers in a Home-Based Palliative Care Model – A Qualitative Study [19]	2020 India India J Palliat Care	Identify and understand the challenges that caregivers face when caring for a terminally ill patient in a home palliative care setting and the mechanisms that facilitated their coping.	Qualitative research N = 24 caregiver	- - It goes without saying that a well-designed caregiver program should be part of any home palliative care service. - - Some areas should be addressed by this programme: - a) Awareness and understanding - b) Conspiracy of Silence - c) Training in Skills for Home Care - d) Preparation for the patient's death - e) Self-care -Mourning
4. Perception of family caregivers of elderly patients about palliative care[20]	2021 Brazil Rev. enferm. UFPE online	To know the perception of caregivers about palliative care.	This is a qualitative, descriptive, exploratory study. N = 11 caregivers	- - 18.18% are unaware of what Palliative Care is and it is necessary to understand this process in order to better approach the patient and family caregiver by the palliative care team. - - There is a need for greater disclosure about what palliative care is, how it is offered and to whom it should be provided. - The caregiver should be kept active in the care process, considering their importance and knowledge in the care decision. The caregiver should feel and be cared for by the team. - The caregiver must feel and also be cared for by the team. - - The team should have a strong and trusting bond with the caregiver. - - Effective communication and support to caregivers make them

				have an understanding of what is offered to the patient and, consequently, to their companions.
5. The family's perception of palliative care [9]	2021 Brazil Rev. Cient. Esc. Estadual Saúde Pública de Goiás Cândido Santiago	To assess the understanding of PC by family members of patients receiving this treatment.	Descriptive qualitative research N= 08 family caregivers	- - The need to inform the general population about the concept of palliative care, in order to remove the stigma associated with this term. - - The promotion of knowledge, effective communication and awareness of family members: this approach is essential for the better management of the team's proposals and adherence to treatment.

After the complete reading of the 14 studies chosen for full reading, 5 articles were included in the qualitative synthesis, in the final sample. Of these, 3 publications (60%) come from national journals and 2 (40%) from international journals.

The studies analyzed predominantly present a qualitative, descriptive and exploratory approach.[9,20,19,18] Only one study adopts a methodological design of cross-sectional observational research.[6] It is important to highlight that only the Pakistani study 6 specifically addresses home palliative care, while the others focus on hospital settings.

After the analysis of the five articles, there is a predominance of female caregivers, and in general it is the wife, sister, or daughter[9.20] and[18] this data agrees with international publications that indicate that the main caregiver is a close relative who assumes this role when a family member falls ill.[21]

Most of the caregivers in the studies have an average age of 40 years and this is corroborated by Cunha's study; Pitombeira; Noronha Panzetti[22] in which the age of the caregivers ranged from 25 to 54 years, with a mean age of 42 years.

Discussion

The articles included in the qualitative synthesis reveal the lack of knowledge among caregivers about the concept of palliative care and highlight the significant impact, as well as the fragility of the interaction and communication between the team and the patient/caregiver. Our findings corroborate those of the World Health Organization (WHO) when they point out that the literature reiterates that knowledge deficits and misunderstandings represent important challenges in the adequate provision of palliative care.[6]

According to Cunha; Pitombeira; Noronha Panzetti[22], when family caregivers have a solid understanding of palliative care principles and practices, they can play a more effective role in patient support and collaboration with the health care team. This not only improves the quality of care but also strengthens the bonds between family caregivers and healthcare providers, promoting a holistic and compassionate approach to the patient.

The studies highlight the importance of understanding palliative care by patients' families. The research of6 shows that, in Karachi, Pakistan, there is still a gap in knowledge and understanding of palliative care among caregivers. This gap was also evident in Brazil.[19.20]

The difficulty in conceptualizing palliative care, pointed out in the selected studies, highlights the need for educational programs to improve awareness about this type of approach, for whom it is intended, and what the objectives of care are[9]. Most family caregivers had not had contact with the concept of palliative care before their family member was receiving this type of approach.[9]

Em uma amostra de 311 cuidadores familiares de adultos beneficiários de cuidados nos Estados Unidos da América, descobriu-se que mais da metade dos cuidadores familiares em 2018 nunca tinham ouvido falar de cuidados paliativos, e isso era mais provável para afro-americanos, hispânicos/latinos e outras raças minoritárias e aqueles com menos de educação universitária [23].

Cerca de 45% dos cuidadores de um dos estudos [6], tinham conhecimento razoável sobre o que são cuidados paliativos. Embora haja a inferência do pouco conhecimento sobre o conceito de cuidados paliativos[20]. relatam que alguns cuidadores percebem o cuidado paliativo como um momento para proporcionar qualidade de vida a seu ente querido, ainda que frente à finitude. Para este grupo de cuidadores familiares, a compreensão sobre o cuidado veio por meio da vivência, da observação e das instruções dadas pela equipe de saúde.

Diante da gama de desafios enfrentados pelos cuidadores de familiares com diagnóstico de doenças que ameaçam a vida, eles gostariam de ter sido apresentados aos cuidados paliativos mais cedo. Apontaram também a necessidade prática de receberem treinamento sobre procedimentos corriqueiros do cuidado. Entende-se que treinar cuidadores para o desenvolvimento de cuidados no domicílio não é uma tarefa fácil, e a sua manutenção requer: educação continuada, avaliação frequente, reuniões com o grupo de tal forma que ocorra troca constante de experiência entre os cuidadores e a equipe de saúde [19].

The work of these authors[19] shows that for many caregivers, the first contact with palliative care occurred abruptly, without further explanation by the attending physician. Most family members and patients were unaware of palliative care.

Discussing with patients and caregivers the potential consequences, risks, and benefits of palliative care provides significant long-term benefits for patients and their caregivers.[22]

The studies listed for this study infer that understanding the principles of palliative care is essential to develop and implement this model of care, because once the concept of palliative care and its benefits is understood, the choice for this type of approach becomes more accessible.

We found that most caregivers have a partial understanding of the holistic approach to palliative care, pointing to two fundamental aspects: the need for health education in palliative care and more effective public policies that ensure this approach for patients and their caregivers.

Study limitations

We believe that the limitation of the study lies in the decision to include only articles that are freely available for download and written in three languages.

Conclusion

Although the literature on palliative care is vast, caregivers' understanding of the concept of this approach is little explored, which was proven by the small sample of the qualitative synthesis.

The reviewed studies highlight the importance of knowing caregivers' understanding of palliative care offered to their loved ones. This knowledge is crucial for providing quality care, ensuring that both patients and their families receive adequate support when facing serious and advanced illnesses.

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