Palliative care amidst the COVID-19 pandemic: challenges and contributions

Cuidados paliativos no contexto da pandemia de COVID-19: desafios e contribuições

Cuidados paliativos en el contexto de la pandemia de COVID-19: desafíos y contribuciones

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Abstract

Objective: To analyze the scientific evidence on palliative care implementation amidst the COVID-19 pandemic.

Method: This is a scoping review based on the methodology proposed by the Joanna Briggs Institute. Virtual Health Library, Web of Science, Scopus, Cumulative Index to Nursing and Allied Health Literature, EBSCO, Embase, PsycInfo® and Science Direct were analyzed using the descriptors "palliative care" and "coronavirus" and the keyword "COVID-19". Thirty studies were selected for analysis.

Results: This review showed strategies for palliative care implementation using protocols and telemedicine, to facilitate communication, and showed how palliative therapy approach has been, revealing the need to promote comfort and welcoming patients and family members in times of pain and grief.

Conclusion: The palliative care principles contribute to comprehensive care, but its implementation amidst the crisis is a challenge. It is important to provide conditions to apply it in the daily life of health services, even in pandemic scenarios.

Resumo

Objetivo: Analisar as evidências científicas sobre a inserção dos cuidados paliativos no cenário da pandemia de COVID-19.

Método: Revisão de escopo baseada na metodologia proposta pelo Instituto Joanna Briggs. Foram analisadas as bases da Biblioteca Virtual da Saúde, *Web of Science*, Scopus, *Cumulative Index to Nursing and Allied Health Literature*, EBSCO, Embase, PsycInfo® e Science Direct, por meio dos descritores "cuidados paliativos" e "coronavirus" e a palavra-chave "COVID-19". Foram selecionados 30 estudos para análise.

Resultados: A revisão evidenciou estratégias para implementação dos cuidados paliativos com a utilização de protocolos e telemedicina, para facilitar a comunicação, e mostrou como tem sido a abordagem da terapêutica paliativista, revelando a necessidade da promoção do conforto e do acolhimento de pacientes e familiares em momentos de dor e luto.

Conclusão: Os princípios dos cuidados paliativos contribuem para o cuidado integral, mas sua implementação no contexto de crise é um desafio. É importante proporcionar condições para aplicá-lo no cotidiano dos serviços de saúde, mesmo em cenários de pandemia.

Resumen

Objetivo: Analizar las evidencias científicas sobre la incorporación de los cuidados paliativos en el escenario de la pandemia de COVID-19.

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Métodos: Revisión de alcance basada en la metodología propuesta por el Instituto Joanna Briggs. Se analizaron las bases de la *Biblioteca Virtual da Saúde*, *Web of Science*, Scopus, *Cumulative Index to Nursing and Allied Health Literature*, EBSCO, Embase, PsycInfo® y Science Direct, mediante los descriptores "cuidados paliativos" y "coronavirus" y la palabra clave "COVID-19". Se seleccionaron 30 estudios para el análisis.

Resultados: La revisión evidenció estrategias para la implementación de los cuidados paliativos con el uso de protocolos y telemedicina para facilitar la comunicación y demostró de qué forma se está realizando el enfoque de la terapia paliativa, que reveló la necesidad de promover el bienestar de pacientes y familiares y acogerlos en momentos de dolor y duelo.

Conclusión: Los principios de los cuidados paliativos contribuyen para el cuidado integral, pero su implementación en el contexto de crisis es un desafío. Es importante proporcionar condiciones para aplicarlo en la cotidianidad de los servicios de salud, inclusive en escenarios de pandemia.

Introduction

The pandemic condition determined by the World Health Organization (WHO) in March 2020 had an intense impact on health, exposing important limitations in terms of health products and professionals trained to deal with coronavirus disease 2019 (COVID-19). Despite the epidemiological profile initially outlined, in addition to individuals over 70 years of age and those with comorbidities, young people and children also began to be affected.(1-3)

Worldwide, the volume of confirmed cases increases exponentially, resulting in stress for health services, as well as an important imbalance between the supply and demand for intensive care beds. This panorama brings up discussions on a topic of difficult assimilation on the part of society: to whom to ensure assistance and technological resources for recovery of the clinical picture imposed by the new coronavirus?

When we consider the right to health as an extensive condition for all citizens, the need for decision-making in such adverse circumstances results in impotence and anguish. Under this scenario, the foundations that guide palliative care can be used as an ethical imperative in resource optimization.

According to the WHO, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with the disease at risk of death, by preventing and relieving suffering, through early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.(4) The relevance of this practice led the WHO itself to update the document Clinical management of COVID-19 and to include a chapter on palliative care, recommending a care plan for COVID-19 and respect for the preferences of patients and their families.(5)

Pandemic situations, such as the current one, require great burden on health services, which could benefit the provision of palliative care.(6) In emergency and humanitarian crisis contexts, measures to alleviate suffering can be neglected due to the immediate need to save lives. However, it is worth mentioning that palliative care is equally essential, and its absence implies flawed and ethically unsustainable coping measures, such as that outlined by COVID-19.(7)

Instituting palliative care becomes a viable option to ensure quality care, while it is necessary to decide who needs intensive care or not to maintain life. On the other hand, given the countless number of people affected by COVID-19 and the presence of complex signs and symptoms, palliative care presents themselves as a possibility of comfort and relief of suffering in the face of uncertain prognoses.(8)

Broadening the discussion about the inclusion of palliative care in the strategies of care for patients attending COVID-19 is necessary, not only because of the pressing requirement of optimization of beds and resources, but also for the right to have ensured dignity and comfort in the face of a life-threatening disease.

This study aims to analyze the scientific evidence on palliative care implementation amidst the COVID-19 pandemic.

Methods

It is a scoping review, a form of knowledge synthesis that addresses an exploratory research issue, aimed at mapping the key concepts (evidence) that support a particular area of research, identifying gaps in existing and emerging evidence and setting goals for future research.(9.10) The construction of this scoping review followed the structure of Peters et al.,(11.12) published by the Joanna Briggs Institute.(13)

To identify the research question, we used Population, Concept and Context strategy, in which "P" corresponds to population/participants (patients with COVID-19); "C" corresponds to the concept to be investigated (palliative care). We chose not to insert the Context, because we sought to explore the evidence of the relationship between COVID-19 and palliative care. Thus, this review considered the following research question: how has palliative care been implemented for patients with COVID-19?

For the purposes of this research, the source of information included studies published in 2020, in any language and that were available electronically in full. Research reports and abstracts published in event annals were defined as exclusion criteria.

The paired search took place in the Virtual Health Library (VHL), Science Direct, Web of Science, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), EBSCO, Embase and PsycInfo®. The descriptors were used according to the terminology of Health Science Descriptrs (DeCS – *Descritores em Ciências da Saúde*) and Medical Subject Headings (MeSH). The keywords "COVID-19" and "COVID 19" were included in searches in order to expand the findings. With these terms, searches were carried out, integrating them through the Boolean operators "AND" and "OR".

The search strategies for each base are described in Chart 1. We chose to search with descriptors in English, because the equation allowed identifying a great amount of articles when compared to searches with descriptors in Brazilian Portuguese and Spanish.

Data were extracted from the articles included in the scoping review by two independent reviewers. The selected articles were organized in a Microsoft Excel database® describing their identification (title, authors, language, country, location, journal, and year); methodological aspects (research design, objectives, sampling, data processing and level of evidence) and critical analysis (results and conclusions).

Chart 1. Search strategies used in the Virtual Health Library, Web of Science, Scopus, Cumulative Index to Nursing and Allied Health Literature, EBSCO, Embase, PsycInfo®, and Science Direct

Database	Search strategies
Virtual Health Library	(tw: (*coronavírus* OR coronavirus OR "covid-19" OR "covid 19")) AND (tw: ("*cuidados paliativos*" OR "*cuidado paliativo*" OR "palliative care"))
Web of Science, Science Direct	(coronavirus OR "COVID-19" OR "COVID 19") AND TOPIC: ("palliative care")
Scopus	(TITLE-ABS-KEY (coronavirus OR "covid-19" OR "covid 19") AND TITLE-ABS-KEY ("palliative care"))
EBSCO, CINAHL	(coronavirus OR "covid-19" OR "covid 19") AND ("palliative care")
EMBASE	("coronavirus"/exp OR coronavirus OR "covid-19" OR "covid 19"/exp OR "covid 19") AND ("palliative care"/exp OR "palliative care")
PsycInfo	Any Field: coronavirus OR Any Field: "COVID-19" OR Any Field: "COVID 19" AND Any Field: "palliative care"

CINAHL - Cumulative Index to Nursing and Allied Health Literature

Controversies were resolved through critical discussion among reviewers. The draft data extraction tool was modified and revised as needed during the process performed for each included study. The searches and the selection process of the studies occurred during the month of April 2020.

As it is a systematic review of scope, according to the methodology used, the methodological quality assessment of the included studies is dispensed with. To prepare the review, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - extension for Scoping Review (PRISMA-ScR)(14) checklist and PRISMA flowchart recommendations were followed.(15)

Results

The research identified 170 potentially relevant studies, of which 25 were removed because they were duplicated. A total of 145 abstracts were analyzed, and 104 published before 2020 were eliminated. Of these, 41 abstracts were assessed for eligibility and, at the end, 30 articles remained for analysis of their full text by two independent reviewers (Figure 1).

The studies' characteristics included in this review are detailed in Chart 2. They were developed in nine countries, with emphasis on the United States (11; 36.6%) and the United Kingdom (8; 26.7%).

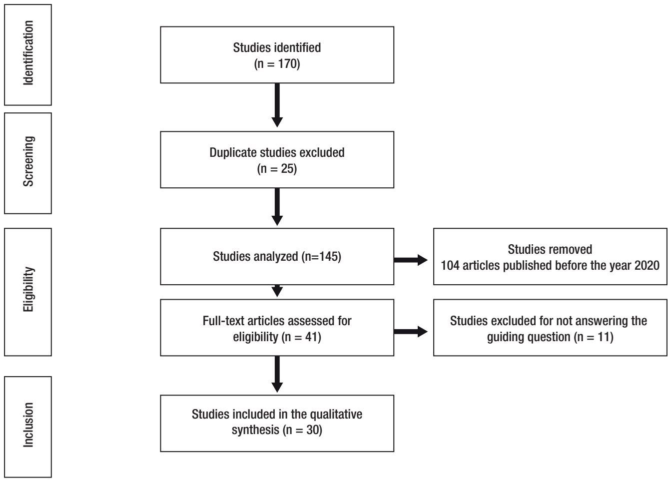

Figure 1. Diagram of the process of inclusion and exclusion of studies

Canada, Germany, Switzerland and Italy published two articles each (6.7%), and Nigeria, China and New Zealand, one article each (3.3%). The journals Journal of Pain and Symptom Management and Royal College of Physicians were the ones that published most on the subject, with 12 (40%) and two (6.7%) articles, respectively. The other journals had only one (3.3%) publication each.

Concerning type of study, seven (23.3%) were expert recommendations; six (20%) were experience reports; five (16.7%) were unspecified literature reviews; four (13.3%) were editorials; two (6.7%) were cross-sectional and descriptive studies. The others were articles of updating, opinion, systematic review, case reports and reflexive. Studies' data source was mostly from scientific literature (16; 53.3%), followed by authors' lived experiences (6; 20%), field research (3; 10%) and telephone contact (1; 3.3%). In editorials, the source was literature and lived experiences (4; 13.3%).

In 16 studies, the concern of palliative care was observed in different populations, such as children (1; 6.2%); adults and elderly (6; 37.5%); cancer patients (1; 6.2%); LGBTQ+ population (1; 6.2%); health professionals (3; 18.7%); palliative care staffs (2; 12.5%). One article (6.2%) addressed both patients as well as other caregivers and health professionals.

Regarding the themes, two categories summarize the main aspects addressed in the studies: "Strategies for implementing palliative care in coping with COVID-19"(17-19,21,23,25,27-32,35,36,38-42.44)(19; 63.3%) and "Palliative therapy amidst the pandemic: challenges and contributions"(16.19-29,31,33,34,36-41,43-45) (24; 80%).

Among the strategies used to implement palliative care in coping with COVID-19, telemedicine and communication between the actors involved,(17-19,21,25,27,28,30,32,35,36,38-42,44) action planning,(17-19,21,23,25,32,35,39-4 1.44) adequate use of personal protective equipment and other materials(19,21,27,28,36,39), and management tool use such as plans, guidelines and protocols stood out.(18,21,23,25,27,28,30-32,35,39,40,42,44)

In relation to the challenges and contributions of palliative therapy amidst the pandemic, pharmacological and non-pharmacological management of the signs and symptoms of patients(19-22,24,25,27,29,31,33,36-39,44) and emotional and spiritual support to patients, family members and/or caregivers were verified.(23,26,34,40,41,43-45) The challenges were related to patients' access to health services,(26,34,36,44) need for training of professionals,(26,27,29,33,36) work overload and lack of resources, as shown in Figure 2.(26,36)

Chart 2. Characterization of articles selected for this scoping review

Authorship	Type of study	Population/sample	Data source
Weaver et al.(16)	Expert recommendations	Children	Literature
Calton et al.(17)	Expert recommendations	Patients in palliative care	Literature
Powell et al.(18)	Expert recommendations	Palliative care staff	Literature
Hendin et al.(19)	Expert recommendations	Patients in palliative care	Literature
Nehls et al.(20)	Expert recommendation	-	Literature
Fausto et al.(21)	Experience report	Health professionals	Lived experience
Ferguson et al.(22)	Updating	Health professionals.	Literature
Borasio et al. (23)	Experience report	Palliative care staff	Lived experience
Rolanda et al.(24)	Experience report	Elderly in nursing homes	Lived experience
Curtis et al.(25)	Opinion paper	Health professionals	Literature
The Lancet(26)	Editorial	-	Literature and lived experiences
Bajwah et al.(27)	Literature review	-	Literature
Salako et al.(28)	Experience report	Cancer patients	Lived experience
Fan(29)	Experience report	NI	Lived experience
Etkind et al.(30)	Systematic review	Patients, caregivers and health professionals	Literature
Fusi-Schmidhauser et al.(31)	Descriptive	Patients with COVID-19 not suitable for ventilation	Field research
Tran et al.(32)	Expert recommendations	-	Literature
Lovell et al.(33)	Cross-sectional	101 patients with COVID-19	Field research
Rosa et al.(34)	Expert recommendations	LGBTQ+ with COVID-19	Literature
Humphreys et al.(35)	Experience report	NI	Lived experience
Constantini et al.(36)	Cross-sectional	16 Italian health institutions	Contact via phone
Davies et al.(37)	Literature review	-	Literature
Sun et al.(38)	Case reports	30 patients with COVID admitted to palliative care unit	Field research
Romanò (39)	Literature review	-	Literature
Radbruch et al.(40)	Editorial	-	Literature and lived experiences
Feder et al.(41)	Editorial	-	Literature and lived experiences
Chidiac et al.(42)	Editorial	-	Literature and lived experiences
Peatel(43)	Editorial	-	Literature and lived experiences
Arya et al.(44)	Literature review	NI	Literature
Wallace et al.(45)	Reflection	-	Literature

NI - not informed; LGBTQ+ - Lesbians, Gays, Bisexual, Transvestite, Transsexual, Transgender and Queer

Some studies are both in the first and second categories, as they presented relevant information for both.

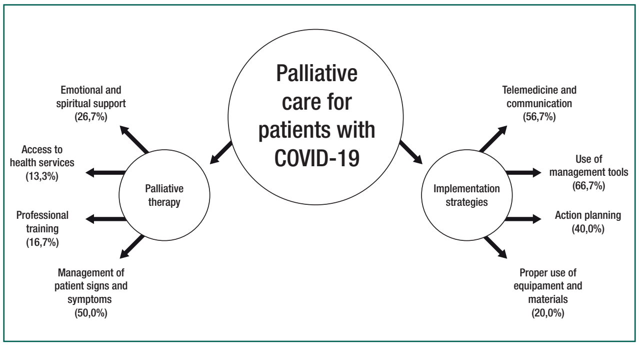

Figure 2. Categories and subcategories identified in the studies

Discussion

Among the limitations, we highlight the lack of prospective studies, which is justified by the acute nature of the disease and the recent appearance of the virus. It is also possible to verify that many articles were based on experiences in some institutions, which may not apply to the reality of other countries. Moreover, the overload of health professionals and the urgent search for cure reinforce the biomedical character of health care, as opposed to palliative care, which emphasize humanization, comfort and quality of life of patients.

Amidst this pandemic scenario, palliative care is different, potent and in multiple forms, with studies and recommendations from experts showing various possibilities in this field of care and research, ranging from palliative care principles to the challenges and weaknesses amid the consequences of COVID-19.

Strategies for palliative care implementation in coping with COVID-19

The growing demand for palliative care due to COVID-19 makes it necessary to establish strategies to provide such care, with the determination of an efficient model for services to minimize risks and expand the scope of palliative approach. The objective is to provide recommendations to health professionals on palliative care; avoid costly intensive treatment, ensuring quality care for those in need; structure services capable of providing fast and effective care and adequately identify who can or cannot benefit from invasive intensive care.(21,23,30)

For this organization to be effective, it is important to implement protocols to identify patients who do not benefit from extreme procedures.(25) It is emphasized that, for the effectiveness of this screening, the services need to have at least one palliative care staff as support for the generalist staffs. In addition, palliative care during the pandemic needs to adapt to an emergency style, as patients can deteriorate rapidly and require immediate decisions and clear treatment plans. In this regard, palliative care must be at the forefront to help make the best decisions, care for families, and provide spiritual support. (31)

The palliative approach was evidenced amidst the pandemic not only by the need to establish protocols for patients affected by COVID-19, but to reorganize aspects related to other patients, such as care of those undergoing cancer treatment,(28) for which the multidisciplinary staff must quickly create, review and update a clinical policy to combat an infection by COVID-19 during treatment.

Health services should rely on offers of comfort medications, have a specialized multidisciplinary staff, optimize space use in hospitals/palliative care clinics, adopt a screening system, appreciate interpersonal relationships, use telemedicine and make use of protocols, being a multifaceted approach. (44)

Concerning social isolation, the staff should make video calls available for patients to contact their families, for the staff to communicate with the family and even for training of professionals or caregivers. In addition to favoring communication, telemedicine is fundamental considering the limitation of Personal Protective Equipment use, as it can favor staff protection and guarantee of adequate care for patients hospitalized with COVID-19.(18,28,30,35,44) To this end, equitable access to technology is required, taking into account the vulnerabilities and limitations of patients and caregivers,(17) with a view to promoting comfort and well-being.(19,27,38)

In response to this reality, frontline professionals should receive training to perform primary palliative care for patients in severe condition, triggering the staff of experts in this type of care whenever necessary. (18,30)

The organization of health services, considering palliative care as a transversal axis in all areas, is essential in coping with the pandemic caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), because there is a need to balance ethics, comfort and quality care. Palliative staffs are fundamental, from screening treatments to the need to provide news and support to family members.

Palliative therapy amidst the pandemic: challenges and contributions

The basic palliative care principles have been increasingly discussed in the scenarios of care, with consequences in different situations and population groups, unveiling its potential during the COVID-19 crisis. The strategies aimed at supporting patients and family members include principles such as relieving symptoms, ensuring comfort in the process of death, offering patient-centered care, caring for patients and their families in relation to physical and spiritual aspects and working with a multidisciplinary staff.(27,41,43)

Although care outcomes cannot be predicted, health professionals should carry out advanced care planning according to the factors that are important for patients' clinical picture. In addition to the adequate control of symptoms, which is a basic and fundamental human right to relieve suffering, regardless the chances of survival, spirituality should be taken into account, whose importance is recognized in the comfort and promotion of patients' and family members' well-being.(27)

The reports of uncertainties regarding the best intervention to be performed, associated with the anxieties produced by the intense workload of health professionals, should not represent impediments to the application of palliative care principles amidst the pandemic. If screening is necessary to prioritize care, when intensive care beds are scarce, it should be necessary to communicate this sensitively and respectfully to patients and their families, suggesting an alternative path.(43)

In addition to the issue related to the infrastructure of services and the uncertainties of the disease, discussing and implementing palliative care are relevant in this context of pandemic, because chronic diseases increase the risk of complications by COVID-19. Elderly patients and/or comorbidities tend to evolve to more complex conditions, especially with acute respiratory distress syndrome.(23,28)

Based on this profile of patients affected by COVID-19, the measures to be improved and implemented more vigorously in health units were related to respiratory distress and pain management (by pharmacological and non-pharmacological means).(20,27,31) Thinking about palliative care in COVID-19 management implies reflecting on decision-making based on patients' clinical status and the implementation of measures for comfort.

When patients are the center and their comfort is focus of care, palliative principles are applied in their essence, providing a holistic and centered look on an individual, surrounded by feelings of fear and uncertainty.(23) Among the care reported for COVID-19 management that overlap with physical care, we highlight the availability of communication channels between family members, providing a moment of farewell and/or hope and breathing exercise use to control anxiety in mild cases.(27,39,41,44)

Assessing the clinical picture and profile of patients with COVID-19 is decisive in decision-making on the indication of invasive procedures and resuscitation. Many prefer to die in their family environment, rather than in an intensive care unit. In such cases, respect for patients' and families' preferences should be an indispensable value and can be identified by the family's consent.(24,25) Palliative care is necessary to provide comfort, as opposed to invasive measures, which often bring suffering and few benefits to patient and/or family.(19)

As a way to mitigate the daily impacts of the pandemic, the therapeutic communication principles should be used to facilitate dialogue with families. This strategy can contribute to minimize stress, favoring the adaptation of new family routines, imposed by sudden changes, including the impossibility of experiencing common practices of social support and religious ceremonies at funerals.(16,28,39,45)

The instability of patients affected by COVID-19, who often present rapid worsening of their clinical picture, required immediate adaptation of health services to cope with the pandemic and health care management for this intense and specific demand.(21,36)

The tension in COVID-19 management also evidenced issues of vulnerability in health, equity in care and gender equality and treatment. It reinforces the palliative care staff's actions in humanizing the practices aimed at patients and respecting their individuality, ensuring that individuals receive high quality care, with respect to their way of seeing and living life.(34)

Conclusion

The palliative care principles contribute to comprehensive care, but its implementation amidst the crisis and pandemic is a challenge, due to the lack of knowledge of health professionals, patients and family members about this approach. Palliative care promotes a holistic view of patients and care, with respect to life and human dignity. This approach contributes to humanized and respectful care, welcoming the preferences of patients and family members. It is important to expand the training of health professionals for palliative care, providing conditions to apply it in the daily life of health services, even in crisis and pandemic scenarios.

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