

## Challenges for palliative care in times of COVID-19: a scoping review protocol

Desafios para os cuidados paliativos em tempos de COVID-19: um protocolo de scoping review

Desafíos para los cuidados paliativos en tiempos de COVID-19: un protocolo de revisión de alcance

Received: 02/17/2023 | Revised: 03/05/2023 | Accepted: 03/09/2023 | Published: 03/14/2023

### Marisa Lourenço

ORCID: <https://orcid.org/0000-0001-5953-788X>  
Nursing School of Porto, Portugal  
Center for Health Technology and Services Research, Portugal  
E-mail: [marisa@esenf.pt](mailto:marisa@esenf.pt)

### Tânia Gomes

ORCID: <https://orcid.org/0000-0002-9900-0160>  
Porto University Hospital Center, Portugal  
E-mail: [tania\\_gomes87@hotmail.com](mailto:tania_gomes87@hotmail.com)

### Fátima Araujo

ORCID: <https://orcid.org/0000-0002-3059-7480>  
Nursing School of Porto, Portugal  
Center for Health Technology and Services Research, Portugal  
E-mail: [araujo@esenf.pt](mailto:araujo@esenf.pt)

### Filipa Ventura

ORCID: <https://orcid.org/0000-0001-5722-5612>  
Nursing School of Coimbra, Portugal  
E-mail: [filipaventura@esenfc.pt](mailto:filipaventura@esenfc.pt)

### Rosa Silva

ORCID: <https://orcid.org/0000-0002-3947-7098>  
Nursing School of Porto, Portugal  
Center for Health Technology and Services Research, Portugal  
Centre for Evidence Based Practice: A JBI Centre of Excellence, Portugal  
E-mail: [rosasilva@esenf.pt](mailto:rosasilva@esenf.pt)

### Abstract

**Introduction:** The COVID-19 Pandemic had a major impact on health personnel, families and the person receiving palliative and end-of-life care. Global measures to reduce contamination have forced a change in the practice. The fear of getting infected, restricted visits and the use of personal protective equipment challenged communication between the multidisciplinary team and the person and family in palliative and end-of-life care. The suffering of an end-of-life experience was compounded by long periods of loneliness. Synthesizing evidence from these experiences can inform decision-making and health policy for future global pandemics. **Objectives:** To map the experience of health personnel, the person and the family in palliative and end-of-life care, during the COVID-19 pandemic. **Methods:** This scope review will follow the JBI methodology for scoping reviews. Two independent reviewers will evaluate the articles and extract and synthesize the data. It will include studies published in Spanish, English and Portuguese, since March 2020. The following electronic databases will be searched: CINAHL Complete, MEDLINE, Scopus, SciELO, Psychology and Behavioral Sciences, MEDIClatina Cochrane Central Register of Controlled Trials and Access Scientific Repository, opened in Portugal. **Results:** This scoping review is expected to include studies that address the experience of health personnel, the person and the family in the context of palliative and end-of-life care during the COVID-19 pandemic. **Conclusion:** This scoping review will analyze and synthesize the available scientific evidence on the experiences of health personnel with people and families in palliative care during COVID-19. It can also be the basis for a systematic review and/or help identify gaps where it may be important to invest in the future. The protocol for this revision is registered with OSF under number OSFHOME-z6agy-v1.

**Keywords:** Palliative care; End-of-life care; COVID-19; Health personnel; Family.

### Resumo

**Introdução:** A Pandemia de COVID-19 teve um grande impacto nos profissionais de saúde, nas famílias e na pessoa em situação paliativa e fim de vida. As medidas globais para reduzir a contaminação, obrigaram a mudança na prática dos cuidados. O medo de contrair a doença, a restrição de visitas e o uso de equipamentos de proteção individual, desafiaram a comunicação entre a equipa, a pessoa e a família em situação paliativa. O sofrimento da experiência de fim de vida, foi agravado por períodos de solidão. A síntese de evidências produzidas, pode informar a tomada de decisão e as políticas de saúde para futuras pandemias globais. **Objetivo:** Mapear a experiência do profissional de saúde, da pessoa e da família em situação paliativa, durante a COVID-19. **Métodos:** Esta revisão seguirá a metodologia JBI para a scoping reviews. Dois revisores independentes irão avaliar os artigos, extrair e sintetizar os dados. Incluirá

estudos publicados em espanhol, inglês e português, desde março 2020. As bases de dados eletrônicas pesquisadas: CINAHL Complete, MEDLINE Complete, Scopus, SciELO, Psychology and Behavioral Sciences, MEDIClatina Cochrane Central Register of Controlled Trials e Repositorio Científico de Acesso Aberto em Portugal. Resultados: Espera-se que esta revisão inclua estudos que abordem a experiência dos profissionais de saúde, da pessoa e da família no contexto dos cuidados paliativos, durante a COVID-19. Conclusão: Esta revisão irá analisar e sintetizar a evidência científica sobre as experiências dos profissionais de saúde, das pessoas e famílias em cuidados paliativos, durante a COVID-19. Também pode ser a base para uma revisão sistemática e/ou ajudar a identificar lacunas onde pode ser importante investir no futuro. O protocolo da revisão está registrado OSF, número OSFHOME-z6agyv1.

**Palavras-chave:** Cuidados paliativos; Fim de vida; COVID 19; Profissional de saúde; Família.

### Resumen

**Introducción:** La Pandemia del COVID-19 tuvo un gran impacto en los profesionales de la salud, familias y personas en situaciones paliativas y al final de la vida. Las medidas globales para reducir la contaminación forzaron un cambio en la práctica del cuidado. El miedo a contraer la enfermedad, la restricción de visitas y el uso de equipos de protección personal, desafiaron la comunicación entre el equipo, la persona y la familia en situación paliativa. El sufrimiento de la experiencia del final de la vida se vio agravado por períodos de soledad. La síntesis de la evidencia producida puede informar la toma de decisiones y las políticas de salud para futuras pandemias mundiales. **Objetivo:** Mapear la experiencia del profesional de la salud, la persona y la familia en situación paliativa, durante la COVID-19. **Métodos:** Esta revisión seguirá la metodología JBI para las scoping review. Dos revisores independientes evaluarán los artículos, extraerán y sintetizarán los datos. Incluirá estudios publicados en español, inglés y portugués, desde marzo de 2020. Las bases de datos electrónicas buscadas: CINAHL Complete, MEDLINE, Scopus, SciELO, Psychology and Behavioral Sciences, MEDIClatina Cochrane Central Register of Controlled Trials y Repositorio Científico de Access Aberto em Portugal. Resultados: Se espera que esta revisión incluya estudios que aborden la experiencia de los profesionales de la salud, la persona y la familia en el contexto de los cuidados paliativos durante el COVID-19. **Conclusión:** Esta revisión analizará y sintetizará la evidencia científica sobre las experiencias de profesionales de la salud, personas y familias en cuidados paliativos durante la COVID-19. También puede ser la base para una revisión sistemática y/o ayudar a identificar brechas en las que puede ser importante invertir en el futuro. El protocolo de revisión está registrado en OSF, número OSFHOME-z6agy-v1.

**Palabras clave:** Cuidados paliativos; Cuidado terminal; COVID 19; Personal de salud; Familia.

## 1. Introduction

The number of people living with advanced chronic diseases has increased gradually along with the great developments in science and technology, that continuously prompt resources to assist persons and families in maintaining their wellbeing (WPCA, 2014).

Palliative care are active and global healthcare interventions delivered by multidisciplinary teams both in internment and domiciliary settings, to people at all ages and their families when experiencing suffering as a consequence of an advanced and progressive, or incurable and serious illness. The main goal of palliative care is to promote wellbeing and quality of life through the prevention and relief of physical, psychological, social and spiritual suffering (WHO, 2002; WPCA, 2014). The person at the end-of-life is considered to have an estimated prognostic of 12 months living, while the person terminally ill has that prognostic reduced to three-six months (WHO, 2002; WPCA, 2014).

Palliative care strives for early identification and rigorous control of suffering and anguish related to the health conditions that threaten or limit life. They are a global imperative of health and equity (Knaul et al., 2018), and are therefore considered a basic human right (Al-Mahrezi & Al-Mandhar, 2016).

Palliative care demands an active intervention in the various dimensions of suffering so that it does not become disruptive for the person in extreme end-of-life circumstances. Through palliative care the assistance and support centred to the person and the family is coordinated towards helping to live while optimizing human wellbeing and maximizing care dignity (Amblàs-Novellas et al., 2016; Radbruch et al., 2013). Palliative care conveys a model that is both technical and humanized, highly person-centred and underpinned in four fundamental pillars:

- Rigorous symptom control through pharmacological and non-pharmacological care and treatment strategies (Twycross, 2003; Twycross 2020);

- Adequate communication with the person and the family through strategies of active listening and dignity promotion, to help in finding purpose to the life that remains living. Non-verbal communication cannot be neglected either: the look, the touch, the facial expression and the hands' positioning (Twycross, 2003; Twycross 2020);
- Support to the family by identifying their needs, mobilizing their potential and helping them to prepare to and to deal with their losses before and after the death of their loved one;
- Interdisciplinary team work through the integration of the perspectives and contributes of the various healthcare professionals adequately trained, educated and prepared to answer to the specificity and multitude of needs of the person and his/her family (Twycross, 2003; Twycross 2020);

In 2020 the world was struck by COVID-19, a respiratory infectious disease caused by a new Coronavirus (SARS-CoV2), that came to be considered by the World Health Organisation (WHO) as a global pandemic on March 11<sup>th</sup> 2020, as a consequence of its worldwide dissemination. The COVID-19 Pandemic context experienced through the past two years, led to the reorganization of care and treatment procedures. Specifically, the contact restriction among the person experiencing end-of-life care, their family and the healthcare professionals was a mandatory dissemination prevention measure. The need to avoid contact during the internment as well as in the domiciliary setting, changed greatly the practice of palliative care (Back et al., 2020), particularly concerning the therapeutic relationship between healthcare professional-ill person-family.

The use of the mask and other individual protection equipment (IPE), changed substantially the communication (both verbal and non-verbal) and raised questions concerning the physical distance that limited the possibility of hugging or providing a caring touch. Facial expression was challenged and reduced to the eye's expression, leading to difficulties in the transmission of the message and compromising the use of nonverbal communication that is crucial for a more genuine and comprehensible communication (Marra et al., 2020). Consequently, the person in palliative care experiences brought long periods of time alone, deprived from her/his family. Accordingly, during COVID-19 pandemics, the person in need of palliative care, who keeps her communication and interaction capacities preserved right through near the death, was even more vulnerable with the additional fear of contamination in a forced isolation.

The named experiences led to the elevation of the anxiety level, fear depression and anguish that when ignored might compromise the preservation of dignity and self-esteem of the person experiencing palliative care (Chapman et al., 2020; Chochinov & Bolton, 2020; Patneau & Kett, 2020). The family caregivers similarly reported that the visiting restriction at the palliative care internment units imposed by the COVID-19 pandemic resulted in emotional and psychological suffering (Kim et al., 2021). The physical separation between the person and the family caused by preventive measures of contamination, led to a disruption of the socio-familiar environment (Johnston & Blades, 2020; Powell et al., 2017).

The perception of the infection risk objectified by the IPEs reinforced the physical distance. The contact was restricted to the pharmacological treatment and basic hygiene care, with the consequent loss of the therapeutic importance that a gesture might have, especially for the person who is isolated from the loved ones. This attitude from the healthcare professionals is related to the exceptional situation of experiencing humanitarian crisis caused by the COVID-19 pandemic. The COVID-19 drastically changed healthcare practice (McMillan et al. 2021).

The evidence about the experiences of the healthcare professionals, the person and the family in the context of palliative care during the COVID-19 pandemic might be fundamental findings to define strategies to support palliative care practice during future pandemics, thereby allowing faster decision-making processes in the face of a new crisis. This review will further evidence the influence of the health policy changes in the healthcare practice and in the perceptions of care from the perspective of the person and the family in the palliative care and end-of-life context.

This review will follow the JBI methodology for scoping reviews (Peters et al, 2020) According to JBI, "scoping reviews are carrying out a systematic review" (Peters et al, 2020). An initial search in the JBI Evidence Synthesis, MEDLINE

(PubMed), e CINAHL databases revealed the absence of systematic literature revision about experiences of healthcare professionals, the person and the family in the context of palliative care and end-of-life during the COVID-19 pandemic.

This scoping review will therefore aim to map and examine the experience of the healthcare professionals, the person and the family in the context of palliative and end-of-life care during the COVID-19 Pandemic.

### ***Review questions***

The research questions that will guide this scoping review are defined as follows:

- What are the perceived experiences of healthcare professionals in the context of palliative and end-of-life care during the COVID-19 pandemic?
- What are the perceived experiences of the person in the context of palliative and end-of-life care during the COVID-19 pandemic?
- What are the perceived experiences of the person's family in the context of palliative and end-of-life care during the COVID-19 pandemic?
- What new strategies were used by healthcare professionals in the practice of palliative and end-of-life care during the COVID-19 pandemic?

### ***Inclusion criteria***

Following the JBI methodology for scoping reviews, the P (participants), C (concept), and C (context) mnemonic was applied to define the following inclusion criteria:

- Participants*: This scoping review will consider all the primary studies that have as target population, i) healthcare professionals who integrate multidisciplinary teams of palliative and end-of-life care, ii) people and their families who experienced palliative or end-of-life care. For the purpose of this review, the person experiencing palliative care and end-of-life care is above 18 years old and suffering from an incurable or serious illness, or in an advanced and progressive illness stage.
- Concept*: The review will focus on the experiences of practicing palliative and end-of-life care from the perspective of healthcare professionals, including new strategies that were implemented to improve quality of care. Moreover, the review will also attend to the experiences of the person and the family participating in those treatment and care activities during COVID-19 pandemics.
- Context*: This review will consider all the settings where palliative and end-of-life care is practiced, namely: palliative and end-of-life internment care units, palliative and end-of-life specialized domiciliary care teams and inter-hospitalar teams of care or support to palliative and end-of-life care.

### ***Exclusion criteria***

Literature that does not report on the SARS-COV-2 Pandemic period will be excluded.

## **2. Methodology**

The proposed scoping review will be conducted following JBI methodology (Tricco et al., 2018; and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018). This scoping review protocol aims to map the available scientific evidence on the subject under study (Peters et al., 2020).

## **2.1 Types of sources**

This scoping review will consider quantitative, qualitative and mixed methods study projects for inclusion. It will consider analytical observational studies, including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies. It will also consider descriptive observational study designs, including case series, individual case reports, and descriptive cross-sectional studies and systematic reviews. All studies published in English or Portuguese will be considered for inclusion and the search will start in March 2020, to increase the specificity of the search strategy with regard to COVID-19 related outcomes.

## **2.2 Search strategy**

The search strategy will aim to locate published and unpublished studies. A two-phase approach will be implemented to locate published and unpublished studies. As an initial limit, a search will be performed in the MEDLINE (by PubMed), CINAHL (by EBSCOhost) and JBI Evidence Synthesis databases, to identify the words of the text contained in the titles and abstracts of relevant articles (first phase). The keywords/words from the text contained in the titles and abstracts of relevant articles and the indexing terms used to describe the articles will be used to develop a complete search strategy (phase two). The search strategy, including all identified keywords and indexing terms, will be adapted for each information source included. Searchable databases include MEDLINE (by Pubmed), CINAHL Complete (by EBSCOhost), Psychology and Behavioral Sciences Collection (by EBSCOhost), Medclatina (by EBSCOhost), and the Cochrane Database of Systematic Reviews. Unpublished literature will be searched in the RCAAP (Portuguese Open Access Scientific Repository). In Table 1 we describe the complete search strategy carried out in the database, CINHALL Complete, on 19<sup>th</sup> January 2022. Where 217 papers obtained.

**Table 1 - Search strategies and quantity of retrieved papers in CINHAI Complete (EBSCOhost).**

	<b>Context Descriptors</b>		<b>Concept Descriptors</b>	<b>Limiters</b>
<b>S1</b>	(MH "hospice and palliative nursing")	T1	"Covid-19"	Publication of 2019/2022
<b>S2</b>	(MH "palliative care")	T2	"Covid-19 pandemic"	Expanders: Equivalent Subjects
<b>S3</b>	(MH "Terminally ill Patients")	T3	"coronavirus Disease 2019"	All adult: 19 + years
<b>S4</b>	"end-of-life care"			English language
<b>S5</b>	"Palliative Medicine"			Search mode: Boolean Phrase
<b>S6</b>	(MH "Hospice and palliative Nurses")			Subject terms: palliative care; COVID-19; COVID-19 pandemic
<b>S7</b>	(MH "Hospice care")			
<b>S8</b>	(MH "terminal care")			
<b>S9</b>	"Palliative"			
<b>S10</b>	"end-of-life"			
<b>S11_TI</b> (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10) OR AB (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10)				
((MH "hospice and palliative nursing") OR (MH "palliative care") OR (MH "Terminally ill Patients") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice and palliative Nurses") OR (MH "Hospice care") OR (MH "terminal care") OR "Palliative" OR "end-of-life")) OR AB ((MH "hospice and palliative nursing") OR (MH "palliative care") OR (MH "Terminally ill Patients") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice and palliative Nurses") OR (MH "Hospice care") OR (MH "terminal care") OR "Palliative" OR "end-of-life"))				
<b>T4 (T1 OR T2 OR T3) OR AB (T1 OR T2 OR T3)</b>				
TI (("COVID-19") OR ("COVID-19 pandemic") OR ("Coronavirus Disease" 2019)) OR AB (("COVID-19") OR ("COVID-19 pandemic") OR ("Coronavirus Disease 2019"))				
<b>S11AND T4</b>	((MH "hospice and palliative nursing") OR (MH "palliative care") OR (MH "Terminally ill Patients") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice and palliative Nurses") OR (MH "Hospice care") OR (MH "terminal care") OR "Palliative" OR "end-of-life")) OR AB ((MH "hospice and palliative nursing") OR (MH "palliative care") OR (MH "Terminally ill Patients") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice and palliative Nurses") OR (MH "Hospice care") OR (MH "terminal care") OR "Palliative" OR "end-of-life")) AND TI (("COVID-19") OR ("COVID-19 pandemic") OR ("Coronavirus Disease 2019")) OR AB ("COVID-19 pandemic") OR ("Coronavirus Disease 2019"))			

**RESULTS: 217 ARTICLES (S11 AND T4)**

Source: Authors.

The search strategies, performed on 19<sup>th</sup> January 2022, on MEDLINE Complete (by PubMed), retrieved 747 articles as confirmed by the Table 2.

**Table 2 - Search strategies and quantity of retrieved papers, in MEDLINE Complete.**

	<b>Context Descriptors</b>		<b>Concept Descriptors</b>	<b>Limiters</b>
<b>S1</b>	(MH "hospice and palliative care nursing")	T1	"COVID-19"	Publication of 2019/2022
<b>S2</b>	(MH "palliative care")			Expanders: Equivalent Subjects
<b>S3</b>	(MH "Terminally ill")			All adult: 19 + years
<b>S4</b>	"end-of-life care"			English language
<b>S5</b>	(MH "Palliative Medicine")			Search mode: Boolean Phrase
<b>S6</b>	(MH "Hospice care")			Subject terms: palliative care; COVID-19; COVID-19 pandemic
<b>S7</b>	(MH "terminal care")			
<b>S8</b>	(MH "Hospices")			
<b>S9</b>	"end-of-life"			
<b>S10 TI</b> (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10) OR AB (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9) = ((MH "hospice and palliative care nursing") OR (MH "palliative care") OR (MH "Terminally ill") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice care") OR (MH "terminal care") OR "Hospices" OR "end-of-life")) OR AB (MH "hospice and palliative care nursing") OR (MH "palliative care") OR (MH "Terminally ill") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice care") OR (MH "terminal care") OR "Hospices" OR "end-of-life"))				
<b>S10AND T2</b>	((MH "hospice and palliative care nursing") OR (MH "palliative care") OR (MH "Terminally ill") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice care") OR (MH "terminal care") OR "Hospices" OR "end-of-life")) OR AB (MH "hospice and palliative care nursing") OR (MH "palliative care") OR (MH "Terminally ill") OR "end-of-life care" OR "Palliative Medicine" OR (MH "Hospice care") OR (MH "terminal care") OR "Hospices" OR "end-of-life")) AND TI ("COVID-19")			

**RESULTS: 747 ARTICLES (S10 AND T2)**

Source: Authors.

The complete search strategy in the Psychology and Behavioral Sciences Collection, Mediclatina and Cochrane Database of Systematic Reviews (EBSCOhost) databases, on 19<sup>th</sup> January 2022, retrieved 74 articles. It is detailed in Table 3.

**Table 3** - Base de dados Psychology, Mediclatina Cochrane Database of Systematic Reviews (by EBSCOhost).

	<b>Context Descriptors</b>		<b>Concept Descriptors</b>	<b>Limiters</b>
<b>S1</b>	"Palliative care"	T1	"COVID-19"	Revistas acadêmicas
<b>S2</b>	"end of life care"	T2	"2019-COVID"	Publicação de 2019/2022
<b>S3</b>	"terminal care"	T3	Sars-cov-2"	Expansores: Assuntos equivalentes
<b>S4</b>	"hospice care"	T4	"cov-19"	Modos de busca - Booleano/Frase
<b>S5</b>	"Palliative treatment"			
<b>S6 TX (S1 OR S2 OR S3 OR S4 OR S5) T5 TX (T1 OR T2 OR T3 OR T4)</b>				
<b>S6 AND T5</b>	TX ("palliative care" or "end of life care" or "terminal care" or "hospice care" or "palliative treatment") AND TX ("COVID-19" or "2019-cov" or "sars-cov-2" or "cov-19")			
<b>RESULTS: 74 ARTICLES (S6 AND T5)</b>				

Source: Authors

### 2.3 Study selection

Following the full search, all the retrieved studies will be compiled and uploaded in Mendeley® Desktop V1.19.8 and removed duplicates. Then the articles will be imported into Rayyan QCRI (Qatar Computing Research Institute [Data Analytics], Doha, Qatar). Thereafter, titles and abstracts will be screened by two reviewers, independently, to assess eligibility according to the inclusion criteria for the review. The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text papers that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the scoping review and presented in a PRISMA-ScR flow diagram (Tricco et al., 2018).

### 2.4 Data extraction

Data will be extracted from the studies by two independent reviewers using the methodology proposed by the JBI (Peters et al., 2020). Any disagreements that arise between the two reviewers will be resolved through discussion or with a third reviewer as necessary. The data extraction tool developed by the reviewers based on the review objectives and questions (Table 4) will be modified and revised as necessary during the data extraction process for each included document. Modifications will be detailed in the full scope review report. The extracted data will include specific details about the methods, participants, concept and context of the study. The authors of the works will be contacted to request missing or additional data, when necessary.

**Table 4 - Data extraction tool.**

<i>Scoping review title</i>
Challenges for palliative care in times of COVID-19: a scoping review
<i>Review objective(s)</i>
To map and examine the experience of the healthcare professionals, the person and the family in the context of palliative and end-of-life care during the COVID-19 Pandemic.
<i>Review question(s)</i>
-What are the perceived experiences of healthcare professionals in the context of palliative and end-of-life care during the COVID-19 pandemic? -What are the perceived experiences of the person in the context of palliative and end-of-life care during the COVID-19 pandemic? -What are the perceived experiences of the person's family in the context of palliative and end-of-life care during the COVID-19 pandemic? -What new strategies were used by healthcare professionals in the practice of palliative and end-of-life care during the COVID-19 pandemic?
<i>Inclusion/ exclusion criteria</i>
<i>Population</i>
This scoping review will consider studies involving healthcare professionals, the person and family in the context of palliative and end-of-life
<i>Concept</i>
Experiences of practicing palliative and end-of-life care from the perspective of healthcare professionals, including new strategies that were implemented to improve quality of care.
<i>Context</i>
All the settings where palliative and end-of-life care is practiced
<i>Types of evidence source</i>
This scoping review will consider quantitative, qualitative and mixed methods study projects for inclusion. It will consider analytical observational studies, including prospective and retrospective cohort studies.
Author(s)
Year of publication
Country origin of source evidence
Aims/purpose
Types of evidence source
Population
<i>Results extracted from the source of evidence according to the concept under analysis</i>
Experience/perception of health professionals in CP during COVID-19
Experience/perception of the person in a palliative and end-of-life situation during COVID-19
Experience/perception of the family in a palliative and end-of-life situation during COVID-19
New strategies used by health professionals in the practice of PC during COVID-19
Other results

Source: Authors.

## 2.5 Data analysis and presentation

The extracted data will be presented in table form and organized according to the research questions. To answer the proposed research questions, the results will be classified into the following categories: year of publication, country, objective, participants with sample size; thematic analysis of the experiences reported from the perspective of the groups of each participant (health professionals, person, family), and new strategies adopted in the practice of health care. A narrative will accompany the tables of results and describe characteristics of the body of literature.

## 3. Results and Discussion

This scoping will focus on the perceived experiences of health professionals, the person and the family in the context of palliative and end-of-life care during the COVID-19 pandemic. It is expected to contribute to systematize the available scientific evidence and identify possible research gaps. A limitation of this review is that it will only consider studies published in Portuguese, Spanish and English. However, for a broader approach, mapping all the information described in the literature,



studies from any geographic area since January 2020, when the COVID-19 pandemic started. As scoping reviews do not seek to assess the methodological quality of the studies included for analysis, recommendations for clinical practice cannot be issued (Arksey & O'Malley, 2005). However, the authors can describe any relevant limitations for the development of future studies on the topic, whether primary studies or systematic reviews.

#### 4. Conclusion

This scoping review will evaluate and synthesize the available evidence on the experiences of health professionals, individuals and families, in the context of palliative care, during the COVID-19 pandemic. The review will provide useful information on the strategies used by health professionals to reduce the negative consequences of social isolation. Health institutions, in order to avoid contamination by the disease, adopt restrictive measures that go against the philosophy of palliative care. Because PC place relationship communication as a fundamental pillar of care. Furthermore, this scoping review can inform the general scientific community and contribute to health management policies in pandemic circumstances. In this perspective, and with a focus on implications for research, systematizing the evidence can be the basis for a systematic review and/or help clarify gaps where it may be important to invest in the future. We suggest future research focused on the effectiveness of intervention strategies implemented by health professionals in the context of palliative care during COVID-19, to reduce the isolation time of patients and their families in future pandemic situations.

#### References

- Al-Mahrezi, A., & Al-Mandhari, Z. (2016) Palliative care: Time for action. *Oman Medical Journal*, 31(3), 161–163. <https://doi.org/10.5001/omj.2016.32>
- Ambiàs-Novellas J., Murray S.A., Espauella J, Martori JC, Oller R, Martínez-Muñoz M, Molist N, Blay C, Gómez-Batiste, X. (2016) Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-sectional study of prognostic indicators related to end-of-life trajectories. *BMJ Open*, 6 (9): e012340. [10.1136/bmjopen-2016-012340](https://doi.org/10.1136/bmjopen-2016-012340)
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19 - 32.
- Back A, Tulskey J. A., & Arnold R M. (2020) Communication skills in the age of COVID-19. *Ann Intern Med*, 172(11), 759-760
- Barr, L. L. B., Christian, R., Palokas, M., & Hinton, E. (2022). COVID-19 challenges and changes for home care agencies and providers. *JBI Evidence Synthesis*, Publish Ahead of Print, 1–7. <https://doi.org/10.11124/jbies-21-00146>
- Chapman, M., Russell, B., & Philip, J. (2020). Systems of Care in Crisis: The Changing Nature of Palliative Care During COVID-19. *Journal of bioethical inquiry*, 17(4), 761–765. <https://doi.org/10.1007/s11673-020-10006-x>
- Chochinov, H. M., Bolton, J., & Sareen, J. (2020). Death, Dying, and Dignity in the Time of the COVID-19 Pandemic. *Journal of palliative medicine*, 23(10), 1294–1295. <https://doi.org/10.1089/jpm.2020.0406>
- Johnston, B., & Blades, S. (2020). COVID-19: using 'knitted hearts' in end-of-life care to enable continuing bonds and memory making. *International journal of palliative nursing*, 26(8), 391–393. <https://doi.org/10.12968/ijpn.2020.26.8.391>
- Kim G.L., Berall A., Gardner S., Brookes J., Natadiria M., & Perri G.A. (2021). The COVID-19 pandemic and palliative care units: A cross-sectional survey of the informational needs of caregivers. *Palliat Med*, 35(3):627-631. [10.1177/0269216321989562](https://doi.org/10.1177/0269216321989562). Epub 2021 Jan 22. PMID: 33482701.
- Knaut, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Jiang Kwete, X., Arreola-Ornelas, H., Gómez-Dantés, O., Rodríguez, N. M., Alleyne, G. A. O., Connor, S. R., Hunter, D. J., Lohman, D., Radbruch, L., Del Rocío Sáenz Madrigal, M., Atun, R., Foley, K. M., Frenk, J., Jamison, D. T., Rajagopal, M. R., & Lancet Commission on Palliative Care and Pain Relief Study Group (2018). Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: *Lancet Commission report. Lancet (London, England)*, 391(10128), 1391–1454. [https://doi.org/10.1016/S0140-6736\(17\)32513-8](https://doi.org/10.1016/S0140-6736(17)32513-8)
- Marra, A., Buonanno, P., Vargas, M., Lacovazzo, C., Ely, E. W., & Servillo, G. (2022). How COVID-19 pandemic changed our communication with families: Losing nonverbal cues. *Critical Care*, 24(1), 1–2. <https://doi.org/10.1186/s13054-020-03035-w>
- McMillan, K., Wright, D. K., McPherson, C. J., Ma, K., & Bitzas, V. (2021). Visitor Restrictions, Palliative Care, and Epistemic Agency: A Qualitative Study of Nurses' Relational Practice During the Coronavirus Pandemic. *Global qualitative nursing research*, 8, 23333936211051702. <https://doi.org/10.1177/23333936211051702>
- Patneau, A., & Kett, J. (2020). Cultural Responsiveness and Palliative Care during the COVID-19 Pandemic. *Palliative medicine reports*, 1(1), 171–173. <https://doi.org/10.1089/pmr.2020.0049>

Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI evidence synthesis*, 18(10), 2119-2126. <https://doi.org/10.11124/JBIES-20-00167>.

Powell, R. A., Schwartz, L., Nouvet, E., Sutton, B., Petrova, M., Marston, J., Munday, D., & Radbruch, L. (2017). Palliative care in humanitarian crises: always something to offer. *Lancet (London, England)*, 389(10078), 1498-1499. [https://doi.org/10.1016/S0140-6736\(17\)30978-9](https://doi.org/10.1016/S0140-6736(17)30978-9).

Radbruch L., De Lima L., Lohmann D., Gwyther E., & Payne S. (2013) The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. *Palliat Med*, 27(2):101-2. [10.1177/0269216312473058](https://doi.org/10.1177/0269216312473058).

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akil, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., & Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467-473. [https://doi.org/10.7326/M18-0850/SUPPL\\_FILE/M18-0850\\_SUPPLEMENT.PDF](https://doi.org/10.7326/M18-0850/SUPPL_FILE/M18-0850_SUPPLEMENT.PDF).

Twycross, R. (2003) *Cuidados Paliativos*. (2a ed.), Climepsi Editores;

Twycross, R. (2020) Palliative care: what, who, when, how? *WMA J*, 66(2),25-28 [https://www.wma.net/wp-content/uploads/2020/05/newwmj\\_2\\_2020\\_WEB.pdf](https://www.wma.net/wp-content/uploads/2020/05/newwmj_2_2020_WEB.pdf)

World Health Organization [WHO] (2002). National cancer control programmes: policies and managerial guidelines [Internet]. Geneva: World Health Organization. <https://www.who.int/cancer/publications/nccp2002/en/>.

Worldwide Palliative Care Alliance [WPCA] (2014). Global atlas of palliative care at the end of life [Internet]. London: Worldwide Palliative Care Alliance. [https://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)