

PROTOCOL

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# End-of-life care for people with chronic obstructive pulmonary disease: a scoping review protocol

Kotoko Minami<sup>1\*</sup>, Chihiro Unozawa<sup>1</sup>, Arina Matsunaga<sup>2</sup> and Tomoko Kamei<sup>3</sup>

## Abstract

**Background** Chronic obstructive pulmonary disease (COPD) is a progressive inflammatory disease that has a typical illness trajectory. Awareness of unique disease courses as well as providing end-of-life care (EOLC) for COPD patients is important as most patients experience varied degrees of suffering toward the end-of-life. The purpose of this scoping review is to map out key concepts, main sources, and types of evidence available in the area of research on EOLC with multiple interventions for people with COPD.

**Methods** This scoping review will be conducted following the latest Joanna Briggs Institute (JBI) guidelines. In addition, this review process will adhere to the preferred reporting items for systematic reviews and meta-analysis extension for scoping reviews (PRISMA-ScR). The initial simple search concepts will be set out as “chronic obstructive pulmonary disease” and “end-of-life care”. Based on the eligibility criteria, Cochrane Central Register of Controlled Trials (CENTRAL), PubMed, CINAHL Ultimate, Embase, and Google Scholar databases will be searched, and all quantitative and qualitative studies of the after-year publication of each electronic database will be included. This process of literature selection will be carried out independently by each researcher. The results will be summarised in a narrative synthesis approach and the gaps and potential biases of the evidence identified by comparing the adopted articles for EOLC with multiple interventions for people with COPD.

**Discussion** This scoping review will outline in detail the evidence and the gaps from primary studies that have been gathered from the qualitative and quantitative literature based on all eligibility criteria. Therefore, the results of this review will contribute to a new field of systematic reviews. Furthermore, providing an outline of an EOLC for COPD in this study may improve the practice of healthcare professionals in this area. Ethical approval and consent are not required as no human participants were involved in this study.

**Systematic review registration** This research has been registered in the Open Science Framework (OSF) (<https://osf.io/upd4a>).

**Keywords** Chronic obstructive pulmonary disease, COPD, End-of-life care, Scoping review, Protocol

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## Background

In 2019, approximately 3.3 million deaths were attributed to Chronic Obstructive Pulmonary Disease (COPD), the third leading cause of death worldwide [1, 2]. It is characterized by dyspnea, cough, and sputum as the main symptoms, often with inexorable airflow limitation [3]. Recently, the increasing prevalence of COPD in low- and middle-income countries and the risks associated with



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the growing older population have become important issues [3]. Although the disease trajectory is generally slow and progressive, acute exacerbation episodes occur occasionally during the terminal stage. However, the illness trajectory is heterogeneous for each COPD patient [4, 5]. Healthcare providers should be aware of these unique disease courses and should prepare to adapt to the multiple care needs of COPD patients. In the guidelines for improving COPD progress, it is important to provide comprehensive long-term disease care management that combines pharmacologic and non-pharmacologic therapies upon appropriate assessment of disease severity [3, 6].

### End-of-life care for people with COPD

General end-of-life care (EOLC) is provided by a team of specialists to patients with a life expectancy of a few weeks to a few months and involves high-quality care that protects the patient's dignity and continuous support until the final moment of death [7]. The latest guidelines suggest that EOLC in COPD includes palliative care, supportive care and advance care planning (ACP), and that these are interventions that should be provided after a comprehensive assessment of the patient's condition and needs [3, 7–9]. While it is true that there are various interpretations of the EOLC concept, in general, it is defined as “palliative care,” which aims to alleviate symptoms of pain and improve quality of life through holistic care [5, 10]. It is likewise defined as “supportive care,” a kind of care that meets both physical and psychological needs while also providing treatment that includes the possibility of extending life. It is important to provide “supportive care” in parallel with treatment over the long term while accurately assessing the patient's needs [7, 11, 12].

Advanced COPD presents highly prevalent symptoms of overall health status, which include dyspnea, fatigue, cough, xerostomia, pain, anxiety, and decreased quality of life [13]. The median number of symptoms in advanced COPD is 14, and the high symptom burden is comparable to lung cancer [14, 15]. In addition, systemic inflammation [16], systemic comorbidities [17], and pulmonary complications [18] are risk factors for COPD, and most patients have one or more comorbidities [17] that contribute to a serious impact on prognosis. In GOLD stages III or IV, acute exacerbations of COPD (AECOPD) occur more frequently and are associated with a higher risk of mortality, which can be triggered by comorbidities [18]. A qualitative study showed that COPD patients during this period were experiencing daily existential distresses such as liminality, lamented life, loss of personal liberty and meaning of life, and existential isolation [19]. Therefore, it is

important to include comprehensive EOLC in the management of COPD disease to alleviate the suffering of COPD patients and to provide healthcare that respects the patient's goals and preferences. However, despite the variety of care needs of COPD patients, EOLC is rarely provided [20, 21].

### Studies supporting end-of-life practices for COPD

ACP is a process of understanding an individual's values, determining future medical care goals and preferences, and sharing them with family members and healthcare providers [22–24]. ACP may improve following the patient's wishes at the end-of-life (EOL) and reduce the psychological burdens on the family members [25]. An important aspect of ACP practice is to facilitate communication between patients and healthcare providers and to ensure that those involved in decision-making understand the patient's goals and preferences for life-sustaining treatment [26, 27]. However, few healthcare professionals initiate ACP regarding EOLC for COPD patients [28, 29]. In a recent review, there are barriers to the initiation of ACP, such as uncertainty of the disease process and lack of criteria for the intervention [30]. Another systematic review shows that COPD patients are increasingly using healthcare resources (e.g., hospitalization, ICU utilization, and prescription medications) in the end-of-life stage [31]. Thus, a lack of discussion about patients' goals and preferences of care may have an impact on inadequate terminal care and disease outcomes at the EOL. Palliative care at home is associated with reduced mortality, acute care utilization, and costs [32]. In cohort studies, palliative care increased deaths at home [33]. In randomized controlled trials (RCTs), ACP improved end-of-life communication [34], and a multidisciplinary team approach increased ACP uptake [35]. Thus, EOLC for people with COPD and their families is important to address the needs of the individual at the EOL and to support their quality of life. Iyer et al. (2022) emphasized the important role of palliative care and recommended its integration into EOLC for COPD patients [5] although only a few studies have conducted a scoping review of the literature focused on EOLC with multiple interventions in COPD. This study aims to map and synthesize the available existing literature focusing on EOLC with multiple interventions for people with COPD and identify the evidence of overview and evaluation methods of comprehensive EOLC. The findings of this study may lead to new insights that will improve the management of COPD in the field of EOLC, and may contribute to improving the stagnant practice of EOLC, presenting new care models, and obtaining new suggestions that will contribute to the formulation of medical policies.

**Objective**

The purpose of this scoping review is to map out key concepts, main sources, and types of evidence available in the area of research on end-of-life care with multiple interventions for people with chronic obstructive pulmonary disease.

**Methods**

This scoping review methodology will be conducted following the latest guidelines by the Joanna Briggs Institute (JBI) [36] to explore the literature describing the EOLC with multiple interventions for people with COPD. In addition, the reporting process of this research will adhere to the preferred reporting items for systematic reviews and meta-analysis extension for scoping reviews (PRISMA-ScR) [37]. This study has been registered in the Open Science Framework (OSF) (<https://osf.io/upd4a>).

**Stage 1: identifying the research question**

We will identify what is known from the existing literature about all aspects of EOLC with multiple interventions for people with COPD. Our scoping review will describe the following research questions:

1. What is the prevalence of receiving EOLC among people with COPD?
2. What are the characteristics of the EOLC interventions that people with COPD?
3. What are the characteristics of the multidisciplinary professional practices of EOLC?
4. How is EOLC defined in the target literature?
5. How is decision-making in EOLC with multiple interventions for people with COPD described in the selected literature?
6. What has been evaluated in EOLC from the perspective of each study?

**Stage 2: identifying relevant studies**

The eligibility criteria in this scoping review are constructed based on the PCC (participants/concept/context) framework focused on EOLC involving multiple interventions for people with COPD (Tables 1 and 2).

**Search strategy**

The search strategy was developed after identifying initial keywords and index terms relevant to the purpose and research questions of this study from previous research with advice from the librarian at St. Luke’s International University. The initial simple search concepts were set out as “chronic obstructive pulmonary disease” and “end-of-life care”. Furthermore, in this scoping review, we will adopt three search processes following the standard JBI

**Table 1** The PCC (participants/concept/context) framework

Participants	People with chronic obstructive pulmonary disease
Concept	End-of-life care involving multiple interventions
Context	End-of-life

systematic review approach. The first step is an initial limited search of Cochrane Central Register of Controlled Trials (CENTRAL), PubMed, CINAHL Ultimate, Embase, and Google Scholar, followed by an analysis of the text words and keywords contained in the titles and abstracts of each of the initial literature sources. The second step will be a search of all relevant databases using the keywords and index terms obtained in the first step of the search with no restrictions on language, publication date, or publication type. Third, we will search for the reference list of all adopted papers and will identify additional literature. In addition, we will include all quantitative studies and qualitative studies of the after-year publication of each electronic database and comprehensively search to identify both published and unpublished literature (Table 3).

**Stage 3: study selection**

All searched articles will be managed using Rayyan software, and duplicate articles will be removed. Titles and abstracts will be screened carefully and irrelevant studies removed based on the eligibility criteria. After selecting potentially relevant studies, reviewers read the full text to make the final decision on inclusion in this review. All of the above processes of literature selection must be carried out independently by the main author (KM) and other reviewers (AM, CU). In case of any disagreement, it will be discussed with a third reviewer (TK). The details of the search decision process result which include the search, removal of duplicate citations, study selection, full retrieval, and additions from reference list searching will show the preferred reporting items for systematic reviews used and the meta-analysis (PRISMA) flow diagram (Fig. 1) [38].

**Stage 4: data extraction**

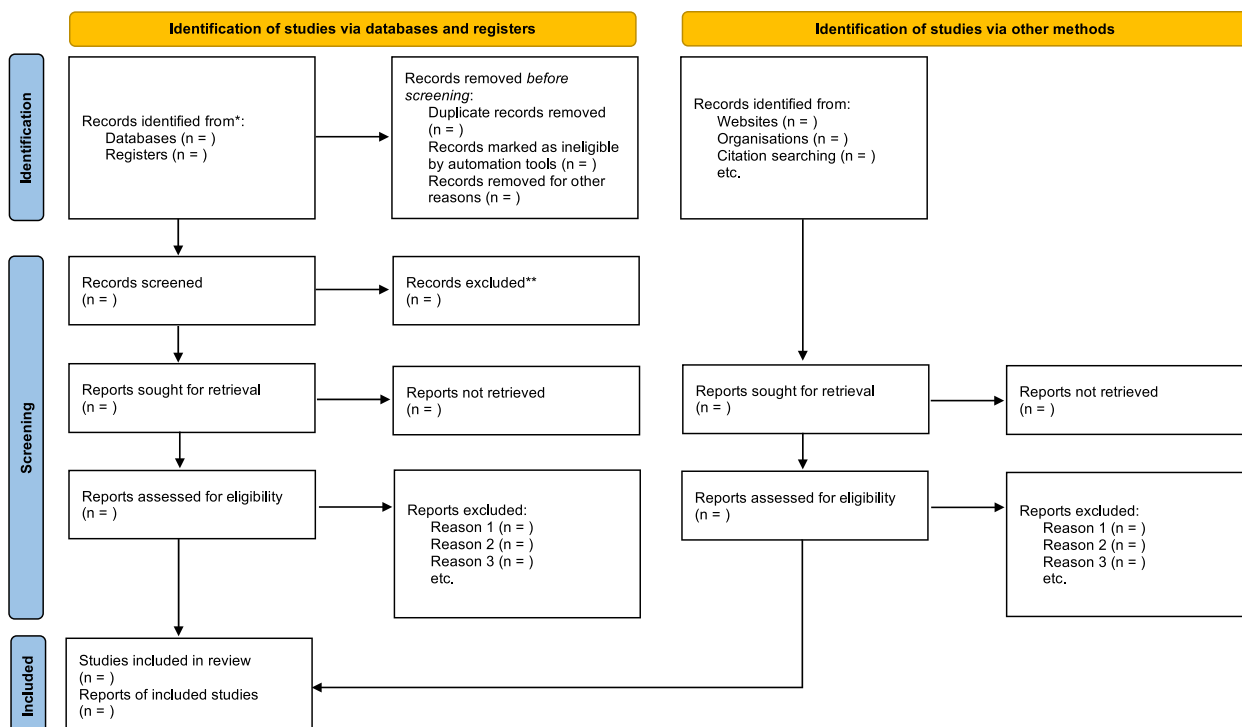
The data from the primary search of included reports will be extracted and charted using a data extraction form created by the main author following the research question and the eligibility criteria of this study [36]. In addition, the extraction and charting of the data process will be conducted independently by the main author.

**Table 2** Eligibility criteria

	Inclusion criteria	Exclusion criteria
Participants	<ul style="list-style-type: none"> <li>• Include people with chronic obstructive pulmonary disease (COPD)</li> <li>• Include adult population (age &gt; 18)</li> <li>• People with COPD in end-of-life care trajectory</li> </ul>	<ul style="list-style-type: none"> <li>• People with under-diagnosed COPD</li> <li>• Adolescents (under 18 years of age)</li> <li>• Studies conducted on participants who were not at the end-of-life phase</li> <li>• Studies that include results regarding diseases other than COPD</li> </ul>
Concept	<ul style="list-style-type: none"> <li>• Including treatments by two or more different healthcare professionals for people with COPD at the end-of-life care trajectory</li> <li>• End-of-life care that includes multiple interventions such as palliative care, supportive care, advance care planning, and spiritual care</li> </ul>	<ul style="list-style-type: none"> <li>• Not including healthcare professionals</li> <li>• Single intervention</li> <li>• Palliative care provided merely to relieve/treat symptoms</li> </ul>
Context	<ul style="list-style-type: none"> <li>• End-of-life</li> <li>• Include any settings of study (i.e., medical facilities, community home health care, nursing home)</li> </ul>	<ul style="list-style-type: none"> <li>• Not related to end-of-life context</li> </ul>

**Table 3** PubMed search strategy

- #1 ("chronic obstructive pulmonary disease"[Title/Abstract] OR "pulmonary disease, chronic obstructive"[MeSH Terms] OR "COPD"[Title/Abstract])
- #2 ("Interdisciplinary"[Text Word] OR "multicomponent"[Text Word] OR "interprofessional"[Text Word] OR "transdisciplinary"[Text Word] OR "comprehensive"[Text Word] OR "integrated"[Text Word] OR "patient care team"[MeSH Terms] OR "interprofessional relations"[MeSH Terms] OR "comprehensive health care"[MeSH Terms] OR "delivery of health care, integrated"[MeSH Terms])
- #3 ("end of life care"[Title/Abstract] OR ("terminal care"[MeSH Terms] OR "hospice care"[MeSH Terms]) OR "supportive care"[Title/Abstract] OR "advance care planning"[Title/Abstract] OR "advance care planning"[MeSH Terms] OR "Advance Directives"[MeSH Terms] OR "shared decision making"[Title/Abstract] OR "decision making, shared"[MeSH Terms] OR "palliative care"[Title/Abstract] OR "palliative care"[MeSH Terms] OR "spirituality care"[Title/Abstract] OR "spiritual care"[Title/Abstract] OR "spiritual therapies"[MeSH Terms])
- #4 #1 AND #2 AND #3



**Fig. 1** PRISMA flow diagram

\*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). \*\*If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools

Afterward, cross-checking of extracted data will be administered with other reviewers (AM, CU), and when disagreements result regarding dissimilarities in terms of data extraction, they will be settled by the reviewers (CU, KM, TK).

The data extraction form is also available on Google Drive for data entry, data sharing, and management by reviewers. If not all the information is available in the articles, the main author will contact the original researcher via email to collect the information necessary for this scoping review.

The details of data from the included study in this review will be presented by adopting and using the collected data form by guidelines [36, 39, 40]. The outline of collecting data that will be extracted from quantitative and qualitative evidence is as follows: (a) the first author(s), (b) title, (c) year of publication, (d) country, (e) study location and setting, (f) aims of the study, (g) details of study methodology, (h) the theoretical background of the study, (i) data analysis approach, (j) date and duration of the study, (k) number of participants and their baseline data, (l) specific details and characteristics of the intervention, (m) details of usual care, (n) full range and timing of outcomes measured, (o) results, (p) adverse events, (q) suggestions made by the author (s), and (r) unreported data (Table 4).

**Stage 5: collating, summarizing, and reporting the results**

This scoping review aims to explore the concept of EOLC with multiple interventions for people with COPD and the structures that underpin this concept. As with systematic reviews, this study will be based on explicit and systematic methods and will identify and review all types of available evidence from existing relevant qualitative and quantitative studies which were collected without restriction on the type of literature. However, as the scoping review will not perform a typical quantitative

synthesis of study data, it will not assess the methodological quality, heterogeneity, or risk of bias of the included studies. All results will be summarized using a narrative synthesis approach.

This scoping review will determine the research methods, study populations, intervention context and practice, evaluation methods, and key findings of the included studies. More importantly, this scoping review will identify from the details of these studies the key elements of comprehensive EOLC with multiple interventions for people with COPD. In addition, a comparison of the articles used in this review will identify the knowledge gaps in the evidence and potential biases [41].

The key conceptual categories will be presented in tables. However, due to the extensive and iterative nature of scoping reviews, the final presentation of data (e.g., using maps, charts, and tables) may be subject to change [36]. Therefore, if the need to revise how results are presented arises during the review, the most appropriate and reasonable way to present these results will be discussed among the researchers. The reasons for any changes will also be provided.

**Discussion**

This scoping review aims to map out EOLC with multiple interventions for people with COPD from available existing literature following the PRISMA ScR checklist. In addition, we will outline in depth the evidence and gaps from primary studies that the qualitative and quantitative literature included based on all eligibility criteria. Identifying the structure and details of EOLC for people with COPD and the methods of evaluation may have implications for the development of standards to improve practice. We also believe that the findings of this review will contribute to the new area of systematic reviews [42]. By providing an overview of an EOLC for COPD, this

**Table 4** Data extraction form

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First author(s)
Title, year of publication
Country
Study location and setting
Aims of the study
Details of study methodology
Theoretical background of the study
Data analysis approach
Date and duration of the study
Number of participants and their baseline data
Specific details and characteristics of the intervention
Details of usual care
Full range and timing of outcomes measured
Key findings on end-of-life care that includes multiple interventions for people with chronic obstructive pulmonary disease
Adverse events

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study will also identify new findings that could improve COPD management in the area of EOLC.

Presenting the characteristics and consequences of specific EOLC concepts for people with COPD has the potential to (a) improve stagnant implementation, (b) present new models of care, (c) provide important suggestions for medical policy development.

The results of this study could clarify what evidence should support EOLC for people with COPD, potentially forming the basis for a new model of practice. Currently, while care in this area is emphasized, its practice is limited, especially in potentially life-threatening chronic diseases. EOLC should be integrated into regular disease management based on the idea of Universal Health Coverage (UHC) [43]. This study may provide important insights into the necessity and feasibility of this integration. By addressing these critical aspects of EOLC for people with COPD, our scoping review aims to contribute significantly to improving patient care, informing policy, and guiding future research in this important area of healthcare.

## Limitations

The potential limitation of this study is that it is possible that studies written in languages other than English and Japanese may not be readily available. Furthermore, in some cases, the results of relevant literature may not provide sufficient data, in which case we will contact the author and attempt to obtain the data. On the other hand, although this study focuses on EOLC, the literature on this topic may take an approach using various research methods, from empirical research to narrative research. In this scoping review, the EOLC of people with COPD involves identifying multiple related concepts, including both physical and psychological aspects, and attempting to find universality among them is an attempt to clarify a very complex structure. This requires an approach from the perspective of so-called ontology and epistemology, and it is inevitable that there will be limitations based on the perceptions of researchers and research subjects. In order to overcome these limitations, we will adhere to the rigorous research methods presented in the methodology section of this study, and we will also aim to present the complex aspects of this research theme as comprehensively and accurately as possible by repeatedly discussing the topic among researchers and seeking to reach a consensus.

## Abbreviations

COPD	Chronic obstructive pulmonary disease
EOL	End-of-life
EOLC	End-of-life care
GOLD	Global initiative for chronic obstructive lung disease
AECOPD	Acute exacerbations of chronic obstructive pulmonary disease
ACP	Advance care planning

ICU	Intensive care unit
RCTs	Randomized controlled trials
JB	Joanna Briggs Institute
PRISMA-ScR	Preferred reporting items for systematic reviews and meta-analysis extension for scoping reviews
HCPs	Healthcare professionals
PCC	Participants/concept/context
CENTRAL	Cochrane central register of controlled trials
CINAHL	Cumulative index to nursing and allied health literature
PRISMA	Preferred reporting items for systematic reviews used and the meta-analysis

## Acknowledgements

The authors would like to acknowledge librarian SS for the database search strategy.

## Authors' contributions

All authors conceived the study protocol process and contributed to the concept. KM and TK designed and drafted the original manuscript of the study. All of the processes of literature selection will be carried out by CU and AM. All authors will review the draft and approve the final manuscript to be published.

## Funding

None.

## Data availability

Data sharing does not apply in this protocol study as no datasets were generated or analyzed during this study. All datasets used and analyzed during this study will be available in the published scoping review article.

## Declarations

### Ethics approval and consent to participate

Ethical approval and consent are not required as no human participants were involved in this study.

### Consent for publications

Not applicable.

### Competing interests

The authors have no conflicts of interest to declare.

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