

R E V I E W

Strategies implemented by informal caregivers to facilitate self-care in patients with chronic obstructive pulmonary disease (COPD): a scoping review protocol

Giovanna Casella¹⁻², Beatrice Salemi¹, Cosimo Franco², Marta Acampora³, Serena Barello⁴, and Massimo Guasconi¹⁻²

¹University of Parma, Department of Medicine and Surgery, Parma, Italy; ²“Azienda Unità Sanitaria Locale” (Local Health Service) di Piacenza, Piacenza, Italy; ³“Università Cattolica del Sacro Cuore”, Department of Psychology, Milan, Italy; ⁴University of Pavia, Department of Brain and Behavioural Sciences, Pavia, Italy

Abstract. *Background and aim:* Chronic obstructive pulmonary disease (COPD) is a disease characterized by persistent respiratory symptoms and airflow limitation. COPD is a significant social and economic burden, and hospital admissions contribute to increased costs. Informal caregivers play a crucial role in supporting COPD patients in their self-care efforts. Therefore, understanding informal caregiver interventions to improve self-care may be helpful in reducing hospitalizations. This is the protocol for a scoping review that aims to map the literature on informal caregiver interventions to facilitate self-care in COPD patients. *Research question:* What are the strategies implemented by informal caregivers to facilitate self-care for patients with COPD? *Methods:* The review will adhere to the methodology outlined by the JBI. A comprehensive search strategy will be executed in PubMed, CINAHL, Embase, Web of Science, Scopus, Cochrane, and PsycINFO. Additionally, grey literature and relevant unpublished documents will be searched to minimize publication bias. Studies describing strategies/actions implemented by informal caregivers to promote self-care in COPD patients from all countries will be included. We will exclude abstracts, editorials, articles on paid caregivers and social and healthcare workers. Two independent reviewers will screen titles, abstracts, and full-text articles based on inclusion criteria. Key data from the selected studies will be extracted using a predefined data extraction table. The results will be aggregated into themes and described qualitatively, figures and graphs may also be presented. The results will be presented according to the PRISMA-ScR. *Review registration:* Open Science Framework <https://doi.org/10.17605/OSF.IO/4TWRM> (www.actabiomedica.it)

Key words: self-care, COPD, Chronic Obstructive Pulmonary Disease, caregiver, scoping review protocol

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a heterogeneous lung condition characterized by chronic respiratory symptoms due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction (1). Typical symptoms include dyspnea, cough and fatigue. Chronicity of

symptoms reduces physical activity, quality of life and increases mortality (1,2).

Furthermore, COPD imposes a substantial social and economic burden worldwide. One of the major drivers of this burden, including most of the COPD treatment costs, is severe exacerbations that result in hospitalization (3-5). Hospitalizations have profound effects on the quality of life and physical function of people with COPD, putting them at risk

of accelerated decline in muscle mass and physical functioning (6). For instance, the annual decline in functional capacity (six-minute walk) was greater in people with COPD who had more than one hospitalization per year compared to those without hospitalizations (7). Therefore, implementing strategies to promote self-care could reduce hospitalizations and improve quality of life for people with COPD.

Evidence supports the benefits of a self-care approach for people with COPD. Self-care interventions can play a valuable role in helping people with COPD readmissions (8).

In light of the above, caregiver support for patients appears to be fundamental. The formal caregiver is a healthcare professional or paid caregiver who provides assistance to non-self-sufficient individuals (9). The term informal caregiver or family caregiver refers to a person who provides non-professional, unpaid care to a loved one who is not self-sufficient or requires long-term assistance due to advanced age and/or disabling chronic conditions (9).

A survey conducted by the National Institute of Statistics (ISTAT) on the topic of work-life balance revealed that in 2018, a total of 12,746,000 individuals aged 18 to 64 years (34.6% of the total population in this age group) in Italy were taking care of children under 15 or sick, disabled, or elderly relatives (10). The informal caregiver's contribution to a patient's self-care has been defined as "the provision of time, effort, and support to another person who needs to perform self-care" (11). The literature shows that an individual's social and family environment is particularly important in shaping his or her cognition and behavior. Informal caregivers are people who have a personal relationship with the person with COPD and often provide, without compensation, help and supervision. Consistent evidence for several disease types indicates that caregiver support influences patient adherence and health outcomes (12).

While self-care behaviors of patients with COPD have been addressed in various studies (13–17), there are few studies on interventions implemented by informal caregivers to contribute to the patient's self-care, which could be taught to improve patients' health outcomes.

The purpose of this review is to map the literature regarding strategies implemented by informal caregivers to facilitate self-care for patients with COPD.

Aims

The objective of this article is to describe the research protocol for a scoping review that aims to map the available literature regarding the strategies implemented by informal caregivers to facilitate the self-care of patients with COPD. Another aim of the review is to describe the strategies, their strengths and limitations.

Methods

Review question

What are the strategies implemented by informal caregivers to facilitate self-care for patients with COPD?

Inclusion criteria

Participants

Patients diagnosed with COPD of all ages who have an informal caregiver.

Paid caregivers, social and social-health workers will be excluded.

Concept

The concept of interest are the strategies implemented by the informal caregivers to promote the patient's self-care.

Context

The review will consider articles that address the strategies implemented by informal caregivers in the home, community, or outpatient settings. Reports concerning hospitals and residential care facilities will be excluded because the informal caregivers' strategies are mediate by health care personnel. There are no restrictions on the geographical origin of the studies.

Type of sources

The scoping review will consider peer-reviewed literature with any study design, including secondary

literature. In order to reduce publication bias, grey literature with identifiable research design will be included. Narrative reviews, abstracts and editorials will be excluded.

Design

The proposed scoping review (18) will be conducted in accordance with the guidelines by JBI for scoping reviews (19,20). The scoping review protocol has been registered on the Open Science Framework: <https://doi.org/10.17605/OSF.IO/4TWRM>.

Search strategies

A first search was done in PubMed in order to identify some relevant articles and evaluate their keywords. Then the definitive search strategy for PubMed was set up and from that the strategies for the other databases were derived. The strategy for PubMed (Table 1) was done blinded by two researchers (MG and MA) other 2 researchers (GC and SB) identified the final strategy by reviewing the 2 proposals.

The search will be carried out in the databases PubMed, CINAHL complete, Embase, Web Of

Science, Scopus, Cochrane library, PsycInfo. The Cochrane CENTRAL registry will be included. Unpublished documents will also be searched through the opendissertation database and a direct search will be made in OA journals not indexed in the included databases. Finally, a citation search will be done starting from the bibliography of the included records.

Study selection

Following the search strategy all identified citations will be collated and uploaded into the online systematic review platform Rayyan (21) and duplicates will be removed. Titles and abstracts will be screened by 2 independent reviewers for assessment against the review inclusion criteria. Potentially relevant sources will be retrieved in full.

The full text of selected citations will be assessed in detail against the inclusion criteria by 2 independent reviewers. Reasons for exclusion of full text studies that do not meet the inclusion criteria (e.g. the article does not highlights interventions by informal caregivers) will be recorded and reported in the scoping review. Any disagreements between reviewers at any stage of the selection process will be resolved through discussion or with a third reviewer. The search results and study inclusion process will be fully reported and will be presented according to the PRISMA-ScR extension (22,23).

Data charting

The data extraction table will be decided a priori, developed, and used to extract data from included studies and other relevant literature (18–20,24). The collected elements will include title, authors, journal, year of publication, origin/country, study design, population characteristics, concept and context, and key results related to the research questions of the scoping review (Table 2). The draft data extraction tool will be modified and reviewed, if necessary, during the data extraction process (24,25). Data extraction will be performed by 2 blinded reviewers. Any disagreements between the reviewers will be resolved through discussion or with the help of an additional reviewer. Authors of the articles included may be contacted to request missing or additional data.

Table 1. PubMed strategy.

PubMed	
	(“Pulmonary Disease, Chronic Obstructive”[Mesh] OR “Chronic Obstructive Lung Disease” OR “Chronic Obstructive Pulmonary Diseases” OR “COAD” OR “COPD” OR “Chronic Obstructive Airway Disease” OR “Chronic Obstructive Pulmonary Disease” OR “Airflow Obstruction Chronic” OR “Airflow Obstructions Chronic” OR “Chronic Airflow Obstructions” OR “Chronic Airflow Obstruction”) AND (“Caregivers”[Mesh] OR “Caregiver” OR “caregivers” OR “Carers” OR “Carer” OR “Care Givers” OR “Care Giver” OR “caregiving” OR “Spouse Caregivers” OR “Spouse Caregiver” OR “Family Caregivers” OR “Family Caregiver” OR “Informal Caregivers” OR “Informal Caregiver” OR “partner” OR “lay caregiver” OR “lay caregivers” OR “care partner” OR “care partners” OR “family member” OR “family members” OR “relatives” OR “peer” OR “social network”) AND (“Self Care”[Mesh] OR “self care” OR “Self-Management”[Mesh] OR “self management” OR “Disease Management”)

Table 2. Example of data extraction table.

Title	Authors	Journal	Year of publication	Origin/Country	Study design	Population Characteristics	Concept	Context	Key results

Data synthesis and presentation

Analysis and representation of results will be carried out in accordance with the guidelines for conducting scoping reviews and according to the guidance provided by other methodological papers (19,20,24,25). The results will be aggregated into themes and described qualitatively, figures and graphs may also be presented (24,25). The final decision on the method of representing the results (e.g. graphs or figures) will be made on the basis of the results after the screening will be completed (19,24,25).

A quality appraisal of the included articles will be done with JBI critical appraisal tools (27).

Conclusion

Through the scoping review whose protocol is described we hope to provide a comprehensive overview of the literature regarding the caregivers' interventions to improve self-care in people with COPD. We'll may also identify possible gaps in the literature related to the topic of the review.

Funding: The project did not receive funding

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

Authors Contribution: GC Substantial contributions to the conception and design of the work; She drafting the work. BS Substantial contributions to the conception and design of the work; She drafting the work. CS He contributed to the conception of the work and to the revision of the paper. MA Substantial contributions to the conception and design of the work. SB Substantial contributions to the conception and design of the work; she reviewed the work. MG Substantial contributions to the conception and design of the work; he reviewed the work

References

1. Celli B, Fabbri L, Criner G, et al. Definition and Nomenclature of Chronic Obstructive Pulmonary Disease: Time for Its Revision. *Am J Respir Crit Care Med.* 2022 Dec 1;206(11):1317–25. DOI: 10.1164/rccm.202204-0671PP
2. O'Donnell DE, Milne KM, James MD, De Torres JP, Neder JA. Dyspnea in COPD: New Mechanistic Insights and Management Implications. *Adv Ther.* 2020 Jan;37(1): 41–60. DOI: 10.1007/s12325-019-01128-9
3. Koul PA, Nowshehri AA, Khan UH, Jan RA, Shah SU. Cost of Severe Chronic Obstructive Pulmonary Disease Exacerbations in a High Burden Region in North India. *Ann Glob Health.* 2019 Jan 22;85(1):13. DOI: 10.5334/aogh.2423
4. Løkke A, Lange P, Lykkegaard J, et al. Economic Burden of COPD by Disease Severity – A Nationwide Cohort Study in Denmark. *Int J Chron Obstruct Pulmon Dis.* 2021 Mar;16:603–13. DOI: 10.2147/COPD.S295388
5. Toy EL, Gallagher KF, Stanley EL, Swensen AR, Duh MS. The Economic Impact of Exacerbations of Chronic Obstructive Pulmonary Disease and Exacerbation Definition: A Review. *COPD.* 2010 May;7(3):214–28. DOI: 10.3109/15412555.2010.481697
6. McAuley HJC, Harvey-Dunstan TC, Craner M, et al. Longitudinal changes to quadriceps thickness demonstrate acute sarcopenia following admission to hospital for an exacerbation of chronic respiratory disease. *Thorax.* 2021 Jul;76(7):726–8. DOI: 10.1136/thoraxjnl-2020-215949
7. Bourbeau J. Reduction of Hospital Utilization in Patients With Chronic Obstructive Pulmonary Disease: A Disease-Specific Self-management Intervention. *Arch Intern Med.* 2003 Mar 10;163(5):585. DOI: 10.1001/archinte.163.5.585
8. Cravo A, Attar D, Freeman D, Holmes S, Ip L, Singh SJ. The Importance of Self-Management in the Context of Personalized Care in COPD. *Int J Chron Obstruct Pulmon Dis.* 2022;17:231–43. DOI: 10.2147/COPD.S343108
9. Cioffi A, Cecannecchia C, Baldari B, Karaboue MAA. Informal caregivers in Italy: the 'phantom zone' of welfare. *Acta Biomed.* 2023 Feb 13;94(1):e2023018. DOI: 10.23750/abm.v94i1.13660
10. ISTAT - Istituto Nazionale di Statistica. Conciliazione tra lavoro e famiglia - anno 2018 [Internet]. [cited 2023 Sep 1]. Available from: <https://www.istat.it/it/files/2019/11/Report-Conciliazione-lavoro-e-famiglia.pdf>
11. Matarese M, Pondoni R, Piredda M, De Marinis MG. Caregivers' experiences of contributing to patients' self-care in Chronic Obstructive Pulmonary Disease: A

- thematic synthesis of qualitative studies. *J Adv Nurs*. 2021 Oct;77(10):4017–34. DOI: 10.1111/jan.14942
12. Bryant J, Mansfield E, Boyes A, Waller A, Sanson-Fisher R, Regan T. Involvement of informal caregivers in supporting patients with COPD: a review of intervention studies. *Int J Chron Obstruct Pulmon Dis*. 2016 Jul;11:1587–96. DOI: 10.2147/COPD.S107571
 13. Reiszadeh I, Abolhassani S, Masoudi R, Kheiri S. The effect of self-care program based on the Orem self-care model on fatigue and quality of life in patients with COPD. *Journal of Nursing and Midwifery Sciences*. 2022;9(4):241–8. DOI: 10.4103/jnms.jnms_170_21
 14. Bugajski A, Frazier SK, Cousin L, et al. Effects of a Digital Self-care Intervention in Adults with COPD: A Pilot Study. *West J Nurs Res*. 2020 Sep;42(9):736–46. DOI: 10.1177/0193945919892282
 15. Pazouki Movakher F, Khanjani MS, Hosseini MA, Bakhshi E, Ebrahimi Barmi B. The Effects of the Home-based Self-care Program Follow-up on Re-hospitalization Frequency and Quality of Life in Patients With Chronic Obstructive Pulmonary Disease. *Iranian Rehabilitation Journal*. 2021 Jun 1;19(2):173–80. DOI: 10.32598/irj.19.2.1347.1
 16. Clari M, Matarese M, Ivziku D, De Marinis MG. Self-Care of People with Chronic Obstructive Pulmonary Disease: A Meta-Synthesis. *Patient*. 2017 Aug;10(4):407–27. DOI: 10.1007/s40271-017-0218-z
 17. Padilha JM, Sousa AP, Pereira FM. Participatory action research: A strategy for improving self-care management in chronic obstructive pulmonary disease patients. *Action Research*. 2016 Sep;14(3):240–56. DOI: 10.1177/1476750315606196
 18. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*. 2005 Feb 1;8(1):19–32. DOI: 10.1080/1364557032000119616
 19. Peters MDJ, Godfrey C, McInerney P, et al. Chapter 11: scoping reviews (2020 version). *JBİ manual for evidence synthesis*, JBİ. 2020;
 20. Peters MDJ, Marnie C, Tricco AC, et al. Updated methodological guidance for the conduct of scoping reviews. *JBİ Evid Synth*. 2020 Oct;18(10):2119–26. DOI: 10.11124/JBİES-20-00167
 21. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Syst Rev*. 2016 Dec;5(1):210. DOI: 10.1186/s13643-016-0384-4
 22. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Int J Surg*. 2021 Apr;88:105906. DOI: 10.1016/j.ijsu.2021.105906
 23. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018 Oct 2;169(7):467–73. DOI: 10.7326/M18-0850
 24. Pollock D, Davies EL, Peters MDJ, et al. Undertaking a scoping review: A practical guide for nursing and midwifery students, clinicians, researchers, and academics. *J Adv Nurs*. 2021 Apr;77(4):2102–13. DOI: 10.1111/jan.14743
 25. Pollock D, Peters MDJ, Khalil H, et al. Recommendations for the extraction, analysis, and presentation of results in scoping reviews. *JBİ Evid Synth*. 2023 Mar;21(3):520–32. DOI: 10.11124/JBİES-22-00123
 26. JBİ Critical Appraisal Tools | JBİ [Internet]. Available from: <https://jbi.global/critical-appraisal-tools>

Correspondence:

Received: 31 August 2023

Accepted: 6 December 2023

Massimo Guasconi, RN, MSN

Azienda USL di Piacenza

Piacenza School of Nursing

Via Taverna 37, 29121 Piacenza, Italy.

University of Parma

Department of Medicine and Surgery

Via Gramsci 14, 43121 Parma, Italy.

Phone: 0523303854

E-mail: massimo.guasconi@unipr.it

ORCID: 0000-0002-8855-8919