

Support and Its Effect for Persons Affected by COPD and Their Next of Kin - an Systematic Integrative Review

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Introduction: Chronic Obstructive Pulmonary Disease (COPD) is an irreversible lung disease. People with COPD and their next of kin are affected in daily life and need support from each other, health care, and the surrounding society.

Objective: This systematic integrative review aims to identify which support is given to persons affected by COPD and/or their next of kin from the health care and surrounding society. A second aim was to evaluate the support.

Methods: A systematic integrative review was conducted to aggregate the knowledge by searching PubMed, CINAHL, PsycINFO, Scopus, and Web of Science databases. Search terms were chronic obstructive pulmonary disease (COPD) and support. The time limit was 2014–2023. The review protocol was registered on PROSPERO (CRD42023462784). The inclusion was selected from the aim, and quality review instruments checked quality. The result was analyzed with a constant comparison method.

Results: Persons with COPD receive support from their next of kin, practically and emotionally. Health care also supplies support through information, knowledge, and different training programs. Health care can be in all types of health care, from hospital and primary care to care in the home, all with varying types of support. The next of kin supplies support to their sick relative, becomes support from health care on a small scale, and wishes for more information, knowledge, and understanding about the disease, symptoms, and treatment. The sick person and their carer want to be acknowledged and supported more on their terms.

Conclusion: Support for next of kin is virtually non-existent. Next of kin needs more support from health care and the surrounding society. Healthcare interventions in the future need to involve the person with COPD and the next of kin in a person-centered approach out of every person's needs and support more on their terms.

Keywords: chronic obstructive pulmonary disease, COPD, next of kin, support, person centered care, integrative review

Introduction

Chronic obstructive pulmonary disease (COPD) is a long-term, irreversible lung condition for which there is currently no cure.^{1,2} COPD is the third leading cause of death worldwide, with 3.23 million people dying from COPD in 2019. Persons with COPD experience reduced lung function, and the severity of the disease is classified using the GOLD stages 1–4 and categories A-E COPD.¹ Living with COPD affects not only those diagnosed but also their family members, leading to a significant symptom burden for the individuals and a caregiver burden for their loved ones.³ The symptom burden impacts the daily lives of people with COPD, affecting their ability to work, engage in leisure activities, and participate in social events.⁴ For family members, caring for someone with a chronic illness often results in increased stress and can be exhausting. A caregiver burden arises when there is an imbalance between stressors and the resources available to cope with those stressors.⁵ This burden is related to self-perception and is multifaceted. Over time, it encompasses financial challenges, conflicts arising from multiple responsibilities, and a lack of social activities. As



a result, caregivers may experience negative consequences, including reduced quality of care, a decline in their quality of life, and deterioration in both physical and psychological health.⁶ The next of kin can be family members, friends, neighbors, and et.al from the workplace. The persons with COPD selected these individuals to provide support.⁷ Support is guidance, help, and understanding from a physical, psychological, and social perspective. A prerequisite for providing support is an understanding and confirmation of people with COPD situations and a sense of sympathy.^{8,9} Many interventions and lung programs have been developed. However, most lung programs are primarily focused on disease treatment^{10,11} and physical activity,^{12,13} and the activities are directed to the person affected by COPD.^{14,15} There is currently limited knowledge about the role and needs of next of kin in the context of COPD. When developing effective healthcare interventions, it is crucial to assess existing interventions and programs and evaluate their effectiveness. This study seeks to answer several key questions: What support is available to individuals affected by COPD? What support is provided to their next of kin? How do both the affected individuals and their next of kin perceive and value the support they receive?

This systematic integrative review aims to identify the types of support available to persons impacted by COPD and/or their next of kin from healthcare providers and the broader community. A second aim was to evaluate the support offered.

Methods

The systematic integrative review¹⁶ was registered with a review protocol on PROSPERO (CRD42023462784), in 2023.¹⁷ Throughout this review PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) was used as guidance.¹⁸ Supporting information is to be found in the Prisma checklist ([Supplementary Material 1](#)).

Search Strategy and Screening

A librarian confirmed the search strategy designed on the inclusion criteria. The librarian also assisted in some database searches. A pre-defined keyword search of the following electronic databases was performed from October to December 2023: PubMed, CINAHL, Psych INFO, SCOPUS, Web of Science. A second database search was undertaken in January 2024 to identify any further published papers meeting the study inclusion criteria. The search terms were Chronic obstructive pulmonary disease or COPD and Support. The persons with COPD are diagnosed in GOLD stage 1–4, A-D or A-E¹ and treated in primary and hospital care. All articles are in the English language, not to be equal to only English-speaking countries.

The studies chosen for inclusion were empirical in nature, incorporating qualitative, quantitative, and mixed-method approaches. These included interpretative, descriptive, correlational, randomized controlled trials, and non-randomized studies published in peer-reviewed journals. However, studies such as protocols, editorials, commentaries, case studies, expert reports, abstracts, conference proceedings, and dissertations were excluded from consideration.

Participants were persons diagnosed with COPD and next of kin to those affected by COPD.

Studies involving healthcare professionals were excluded from this review.

The study selection process is illustrated in [Figure 1](#) using the PRISMA Flowchart.

Two authors, (HJ and CB), screened the titles and abstracts of the studies. Following this, a full-text relevance screening was conducted by two authors (LLJ and CB). After reviewing the titles, abstracts, and full texts, the lead author included 104 studies for quality appraisal. The quality assessment was performed by all three authors (HJ, LLJ, and CB). Any discrepancies regarding the inclusion of a study were discussed within the review team, leading to a final decision on whether to include or exclude each study. Studies excluded after (n=104) ([Supplementary Material 2](#)).

Quality Assessment

Evaluating data and assessing quality in a systematic integrative review is a complex process that requires clear guidance.¹⁹ The following quality assessment tools were used: a Critical Appraisal Checklist for Qualitative Research,²⁰ a Checklist for Quasi-Experimental Studies,²¹ and a Critical Appraisal Checklist for Randomized Controlled Trials (The Joanna Briggs Institute).²² These tools were applied to the relevant components of mixed-method studies. After completing the quality appraisal, a total of 68 studies were included in this review.

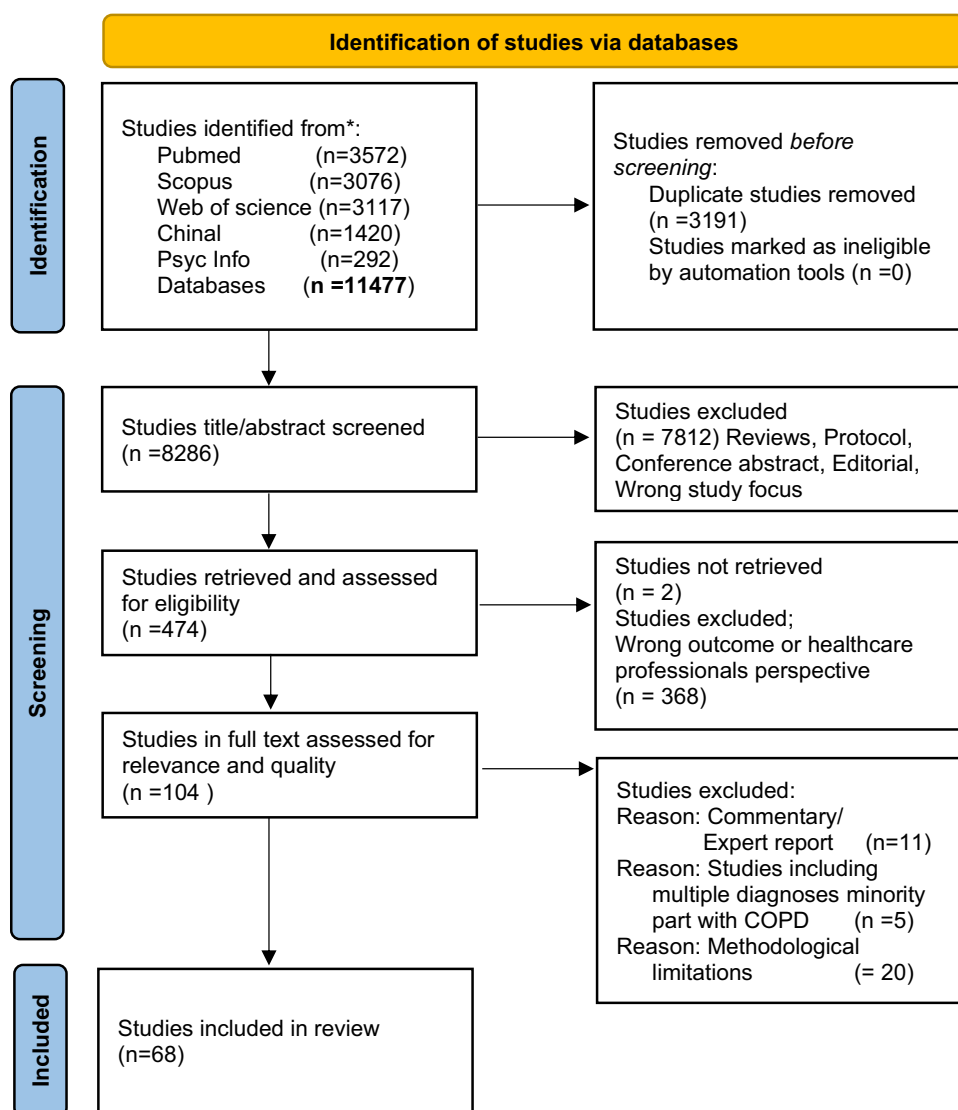


Figure 1 Flowchart of the process.

Data Extraction and Analysis

Data were extracted from each study, including relevant details such as study design, objectives, location, participants, demographic information of next of kin, outcome measures, findings, statistical analyses, and qualitative analyses. In studies that involved individuals with COPD and healthcare professionals, only the results relating to those with COPD, along with their next of kin and healthcare professionals, were included. For studies that examined multiple diseases, only data pertaining to individuals with COPD or their next of kin were utilized.

Data analysis employed a constant comparison method^{23,24} to develop categories relevant to the review's aims. This process involved identifying codes and categories from the qualitative and quantitative studies separately. The quantitative data were synthesized into broader categories based on the type of outcomes evaluated. An effort was made to compare and align these categories with those derived from the qualitative data, culminating in the development of main categories across all study types. This approach allowed for limited consideration of the methodological approaches in each included paper, facilitating the integration and synthesis of findings based on a shared focus on the same phenomenon.

The lead author (HJ) conducted the initial analysis. The second and third authors (LLJ and CB) reviewed the themes for accuracy and representation of the initial data before final confirmation.

Results

Included Studies

Figure 1 illustrates the findings from the literature search. A total of 68 studies were included in this systematic integrative review. Table 1 summarizes the characteristics of the included studies, all of which were published between 2014 and 2023. The studies were conducted in 20 countries worldwide: Australia,^{25–27} Canada^{28–30} China,^{31–34} Colombia,³⁵ Denmark,^{36–39} France,⁴⁰ Germany,^{41,42} Iceland,⁴³ Indonesia,⁴⁴ Iran,⁴⁵ Ireland,^{46,47} Italy,^{48,49} Korea,⁵⁰ New Zealand^{51,52} Norway,^{53–56} Portugal,^{57–59} Sweden,^{53,60–71} The Netherlands,^{72–74} United Kingdom,^{75–85} and USA.^{86–91} Out of these 68 studies, 47 studies performed only qualitative approaches,^{25–31,33,36–39,41–43,45–49,53–57,59,60,62–66,68–70,73,77,78,81,83,86,88–90,92} 15 studies used only quantitative methods,^{32,34,35,40,44,50,51,71,72,74,75,80,84,87,91} and 6 studies utilized mixed methods.^{52,58,61,67,76,79}

Support in Various Forms is Crucial for Persons with COPD

Social support is crucial in self-management and managing daily life.^{31,76,77,87} Social support is a crucial factor in COPD. Persons with COPD who have social support experience depression levels within the normal range, compared to those without social support.⁴⁴ Persons with COPD receive support from different sources, but the primary source is spouses/next of kin as caregivers.⁵⁰ Family members/next of kin or friends to persons with COPD are often described as those providing practical or emotional support.^{41,58,59,65–67,76–78} Emotional support was associated with strengthening physical functionality in basic activities,³⁵ and emotional support is crucial for patients, as it provides them with someone to talk to when they need comfort, wish to express their feelings, discuss challenges, or seek advice.⁷³ Social support is, therefore, a vital factor in managing COPD. Notably, more respondents who reported having social support exhibited depression levels within the normal range compared to those who lacked such support. Additionally, having family members nearby enhances the practical support available to these patients.^{36,37} For those persons with COPD, emotional support in daily life involves maintaining old habits and patterns as much as possible and adjusting tasks as needed with support from relatives, primarily through physical efforts such as rearranging items at home.^{53,54,85} Living with others and being part of a family fosters higher levels of perceived social support, including total support, emotional/informational support, and positive social interaction. These factors are significantly associated with increased step counts and physical activity,^{87,91} and functionality in basic activities were related to informational and emotional support.³⁵ Women with COPD stated that their relationships with significant others, including family members, friends, and medical professionals, greatly enriched their daily lives.⁶³ They emphasized that support in managing everyday activities was essential. Ongoing assistance and encouragement from healthcare professionals and loved ones were deemed necessary for their well-being,⁹² and people with COPD with support around them better manage their illness.³² Some experienced the information and support clinicians gave them poorly, so they were to acknowledge dependence on family and all support they provided,⁸² tips, and financial support.^{33,60,78} Support in peer coaching was seen as a way to learn from and connect with a peer who shares similar life experiences.⁸⁹

A robot used for medical support could be experienced as social support since their family and friends were interested in it and enjoyed visiting to see the person with COPD and the robot. Furthermore, some individuals with COPD appreciated the presence of the robot, as they felt it had a personality and provided good company.⁵¹ Although psychological issues were talked about during nurse-led meetings, no actions were taken to address them. Most individuals with COPD reported feeling well-supported by their families.⁷⁹

In contrast, healthcare professionals were frequently perceived as offering informational support.⁷⁸ Support for persons with COPD is provided through information and knowledge about the diagnosis.⁷⁹ Social support from healthcare providers and social networks is crucial for managing COPD. Many individuals experience anxiety and changes to their daily routines due to their symptoms. Relying on healthcare professionals and peers can provide valuable therapeutic and educational support to help navigate these challenges.^{39,43} They also desire information on how to act during exacerbations and which symptoms to monitor to manage their illness.^{25,55} Support in a consistent healthcare contact providing information from a holistic perspective is desired.^{36,38} Persons with COPD desire support from healthcare, preferably through physical meetings and access to someone they can call when needed. However, they may need more concrete advice from nurses.³¹ Healthcare professionals should offer guidance and support in various

Table 1 Characteristics of Included Studies

Author, Year, Location	Research Aim	Study Design	Sample Characteristics	Main Findings/ Results	Methodological Quality
Aasbø G et al 2016 Norway Ref ⁵³	Explore how caregivers negotiate their role as caregivers with patients and healthcare professionals during acute exacerbations	Qualitative interviews	10 Family caregiver to persons with COPD	The negotiations caregivers participated in and the uncertainty they experienced shed new light on the complexity of their role, and the discrepancy between practice and ideals in healthcare policy regarding collaboration of care.	Medium
Aasbø G et al 2017 Norway Ref ⁵⁴	To show how spouses of COPD patients integrate their tasks as informal carers with their role as spouses and the tensions and challenges involved in this.	Qualitative interviews	10 spouses to persons with COPD	The spouses described their great efforts to re-establish normality and continuity in their everyday lives. Accomplishing this was a delicate process because they faced several dilemmas in this work.	Medium
Abrahamsen Steen C et al 2020 Norway Ref ⁵⁵	To investigate experiences that contribute to enhancing patients' ability to cope with COPD during interdisciplinary in-hospital pulmonary rehabilitation programs.	Qualitative study	17 persons with COPD	Support from healthcare professionals during pulmonary rehabilitation proved to be vital, yet the lectures and consultations they received were described as general and sometimes rushed.	Medium
Alhaddad B et al 2015 UK Ref ⁷⁵	To identify the assistance carers provide to patients with COPD using nebulizer-delivered therapy at home, and the problems experienced that may impact on the safety and effectiveness of therapy and contribute to carer burden.	A cross-sectional, qualitative descriptive study	14 Family caregiver to persons with COPD	Difficulties were described with all aspects of care. Carers reported concerns about medication side effects and the lack of information provided.	Medium
Andersen IC et al 2018 Denmark Ref ³⁶	To explore the meaning of patients' and their family members' experiences of interacting with healthcare providers to their daily self-management over time	Qualitative interviews	10 persons with COPD 7 family members	'Seeking support from healthcare ser"ic's', 'navigating between healthcare prov"ders' and 'collaborating with healthcare providers at home' could entail opportunities to strengthen self-management and hope; however, it could also entail reduced faith in getting the right help and hopelessness.	Medium
Andreou A et al 2020 UK Ref ⁷⁶	To identify how online and offline social networks play a role in the health management of older patients with chronic respiratory conditions, explore the role of support from online peers in patients' self-management, and understand the barriers to and potential benefits of digital social interventions.	Mixed methods study	7 interviewees 5 persons with COPD, 1 person with asthma and 1 asthma + COPD	Using a social network tool as a research tool that can help assess and understand network structure and engagement in the self-management support and could be developed into an intervention to support self-management.	Medium
Apps LD et al 2014 UK Ref ⁷⁷	Clarify by consensus the professional and patient views of expected treatment outcomes for chronic obstructive pulmonary disease and to compare the similarities and differences and identify the potential for adjusting service delivery	Qualitative interview study	15 persons with COPD	Perceptions of COPD by family members posed a challenge to self-care for some participants. Health care professionals should elicit patients' prior disease experiences and utilize spontaneous attempts at disease management in future self-management	Medium
Apps LD et al 2017 UK Ref ⁷⁸	To understand experiences of participation in a supported self management program for chronic obstructive pulmonary disease (COPD).	Qualitative interviews	36 persons with COPD	The importance of education and social support was emphasized at both time points studied, but there were challenges such as comorbidities, ill health of family members and limited maintenance of exercise behaviors over the longer term.	Medium

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Table I (Continued).

Author, Year, Location	Research Aim	Study Design	Sample Characteristics	Main Findings/ Results	Methodological Quality
Bagnasco A et al 2020 Italy Ref ⁴⁸	To understand the experiences and support needs of informal caregivers of patients with chronic obstructive pulmonary diseases chronic obstructive pulmonary disease who return home following an acute exacerbation.	Qualitative interviews	16 informal caregiver to persons with COPD	The results show that carers experience a range of difficulties when caring for their relative at home with chronic obstructive pulmonary disease. Some of these are linked to the physical disruption of their home but many are linked to feelings of inability to cope and the psycho-social impact of the caring role. It also shows how participants felt unsupported by professionals. Focused support for carers is required to enable them to meet these challenges.	Medium
Barenfeld E et al 2022 Sweden Ref ⁶¹	To elucidate patients' experiences of a remote person-centered care (PCC) intervention by deepening the understanding of, if, how and for whom the intervention contributed to meaningful use.	Mixed Methods study	86 persons with COPD or CHF	The combined digital platform and structured telephone support could be helpful in identifying preventive actions to maintain health for people diagnosed with COPD and chronic heart failure but tends to be more meaningful for those diagnosed with COPD	Medium
Blanck E et al 2021 Sweden Ref ⁶²	To clarify the meaning of support given and received by informal carers to relatives with chronic obstructive pulmonary disease or chronic heart failure.	Qualitative study interviews	12 carers to persons with COPD	The comprehensive understanding of the meaning of support for these carers is twofold: it is a self-evident struggle for the good life of their relatives and that they want to be <i>carers in partnership</i> .	Medium
Bove D.G. et al 2016 Denmark Ref ³⁷	To explore how spouses of patients with severe chronic obstructive pulmonary disease experience their role as informal caregiver	Qualitative study Focus groups	22 spouses to persons with COPD	The informal caregiver spouses wanted to provide meaningful care for their partners, but sought knowledge and support from the health professionals.	Medium
Bove D.G. et al 2019 Denmark Ref ³⁸	To explore COPD patients' experiences with a new and altered palliative organization.	Qualitative interviews	10 persons with COPD	Is relevant and meaningful to establish a structure that supports professional relationships between patient, nurse and physician based on patients needs.	Medium
Boyce LA & Prybutok G 2019 USA Ref ⁸⁶	To investigate COPD360social.com, an online forum for COPD patients, to answer the following research questions: what health information do forum members need; what health information sources do they prefer; and how credible is the information exchanged on the forum?	Qualitative study Posted online	732 authors Most persons with COPD?	This study indicates that COPD patients have health information needs and a monitored social health online community that is available to patients 24/7 answers questions that arise at the time of need.	Medium
Broadbent E et al,2019 New Zealand Ref ⁵¹	To investigate the effectiveness of a robot delivering telehealth care to increase adherence to medication and home rehabilitation, improve quality of life, and reduce hospital readmission compared with a standard care control group.	Parallel randomized controlled trial	30+30 persons with COPD	A homecare robot can improve adherence to medication and increase exercise. The robots could be especially useful for patients struggling with adherence.	Medium
Buckingham S et al 2015 UK Ref ⁷⁹	HELping older people with very severe chronic obstructive pulmonary disease	Intervention mixed-method feasibility pilot randomized controlled trial	40 persons with COPD	The HELP-COPD intervention was well received by patients and the concept resonated with professionals, although delivery post discharge overlapped with existing services	High
Chen K-H et al 2016 China Ref ³¹	Exploring the process of self-management for patients with COPD and the factors that impact the efficacy of this process	Qualitative interviews	19 male persons with COPD	Patients naturally become experts with regard to their lives through a process of trial and error. But, healthcare professionals play a key role in the process of self-management and help patients with COPD cope with various problems in their daily lives.	Medium

Chen Z et al 2017 USA Ref ⁸⁷	To determine the association between structural and functional social support and self-care behaviors in adults with COPD.	Quasi-experimental study Secondary analysis	282 persons with COPD	Structural social support, which was measured by reports of living with others and having a caregiver, was respectively associated with higher levels of physical activity and greater participation in pulmonary rehabilitation in adults with COPD.	Medium
Chu H-H et al 2019 Korea Ref ⁵⁰	To analyze relationship of physical and psychological health status between COPD patients and caregivers	Cross-sectional study	72 persons with COPD 72 family caregivers to persons with COPD	For persons with severe COPD, patient self-efficacy, social support, and depression was high. Thus, it is important to assess primary caregiver self-rated health status and chronic disease morbidity by caregiver burden.	Medium
Cooke M et al 2014 UK Ref ⁸⁰	Clarify by consensus the professional and patient views of expected treatment outcomes for chronic obstructive pulmonary disease and to compare the similarities and differences and identify the potential for adjusting service delivery	Feasibility study	24 professionals 52 persons with COPD	Patients consider that services should support them to retain them independence and enable their adaptation to the condition	Medium
Coquart JB et al 2017 France Ref ⁴⁰	Comparing the effects of home-based PR on exercise tolerance, anxiety, depression, and health-related quality of life	Retrospective intervention Study	298 persons with severe to very severe COPD	Despite differences in the medical equipment to treat COPD, home-based PR showed comparable feasibility, safety, and efficacy in all equipment-based groups	Medium
Cox NS et al 2023 New Zealand Ref ⁵²	To describe perceived autonomy support as well as the patient experience of an 8-week telerehabilitation program.	Mixed methods study	142 persons with COPD and 30 persons were interviewed	Telerehabilitation was perceived as an autonomy-supportive environment, in part by making it easier to undertake pulmonary rehabilitation	High
Ekdahl A et al 2020 Sweden Ref ⁹²	To describe women's experiences of living with chronic obstructive pulmonary disease stage III or IV.	Semi-structured interviews	15 female persons with COPD	Significant others gave support and help that was practical and emotional. Women with chronic obstructive pulmonary disease experienced lack of continuous help and support from healthcare professionals	Medium
Ekdahl A et al 2023 Sweden Ref ⁶³	To explore and describe the experiences of close relatives of women with chronic obstructive pulmonary disease stage III or IV and it used qualitative content analysis of individual, semi-structured interviews	Qualitative interviews	9 male next of kin to persons with COPD	Close relatives supported the women both practically and emotionally and they called for tailored information about the illness, considering it as an essential tool for support. The results highlighted that healthy close relatives had difficulty in understanding the experience of living with chronic obstructive pulmonary.	Medium
Farquhar M et al 2017 UK Ref ⁹¹	To identify the educational needs of carers of patients with breathlessness due to advanced disease (ie to establish what these carers want to learn about) in order to provide an evidence base for the intervention's content.	Qualitative interviews dyadic	13 persons with COPD/ 13 next of kin 12 persons with cancer/ 12 next of kin	A cross-cutting theme was relationship management: there were tensions within dyads resulting from mismatched expectations related to most topics. Carers felt that knowledge-gains would not only help them to support the patient better, but also help them to manage their own frustrations, anxieties, and quality of life.	Medium
Fatimah D et al 2019 Indonesia Ref ⁴⁴	To evaluate the relationship between social support and emotional status among patients with chronic obstructive pulmonary disease (COPD).	A cross-sectional method	200 persons with COPD	The results of the analysis of the relationship between social support and emotional status in COPD patients showed that there was no relationship between social support with emotional status (depression) ($p = 0.921$), emotional status (anxiety) ($p = 0.184$), and emotional status (stress) ($p = 0.795$).	Medium

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Table I (Continued).

Author, Year, Location	Research Aim	Study Design	Sample Characteristics	Main Findings/ Results	Methodological Quality
Figueiredo D et al 2015 Portugal Ref ⁵⁷	Exploring the experience of husbands and sons providing care to a family member with moderate-to severe COPD.	A cross-sectional qualitative study interviews	12 male carers to persons with COPD	Main findings suggest that men are committed and dedicated carers; however, differences between husbands and sons related to 'meaning', 'challenges and constraints', 'fears and concerns about the future', 'needs' and 'positive aspects' have emerged. These differences reflect relationship and generational differences and are of relevance when planning adequate community support interventions.	Medium
Figueiredo D et al 2016 Portugal Ref ⁵⁸	To analyze the effects of a family-based pulmonary rehabilitation program on close family caregivers of older subjects with COPD	Mixed methods study	39 persons with COPD	The findings provide valuable evidence to recommend the inclusion of COPD family caregivers in comprehensive pulmonary rehabilitation	Medium
Fitzsimmons DA et al 2016 UK Ref ⁶²	To qualitatively explore the experiences of patients with COPD who had received either a Telehealth-supported or a specialist nursing intervention following their discharge from hospital after an admission for a COPD exacerbation.	Qualitative interviews within a feasibility study	9 persons with COPD +interviews with clinicians	A Telehealth intervention is an acceptable alternative to a more traditional home nursing visit model for monitoring community-based patients with COPD following their discharge from hospital.	Medium
Fotokian Z et al 2017 Iran Ref ⁴⁵	Exploring people's experiences of the empowerment of older people with COPD.	Qualitative study GT	15 elderly persons with COPD 4 Family carer 5 Healthcare providers	Elderly persons with COPD, their family caregivers, and professional team members engaged in "managing life with COPD, "striving to keep abreast of life, "preparing for battle with disease," and "helping to stabilize the elder's life.	Medium
Gabriel R et al 2014 Portugal Ref ⁵⁹	Exploring the perspectives of both patients and family members regarding the impact of chronic obstructive pulmonary disease (COPD) in their family life.	Qualitative study interviews	20 persons with COPD 20 family carers to persons with COPD	The overall findings illustrate the complex interaction between the experience of living with COPD and communication patterns, emotional states, social support and social roles within the family	Medium
Gale NK et al 2015 UK Ref ⁶³	Explore experiences of domiciliary non-invasive ventilation in chronic obstructive pulmonary disease, to understand decision making processes and improve future palliative care.	Qualitative study interviews	20 persons with COPD 4 Family carer 15 Healthcare providers	Data were categorized into four domains – clinical, technical, socio-economic and experiential. Patients reported symptomatic benefit, which generally outweighed negative experiences and led to continued use.	Medium
Garcia Villanueva M et al 2019 Australia Ref ²⁵	To explore the role of coping moderators in self-management of breathlessness crises by people with advanced respiratory disease.	A secondary analysis of semi-structured interview data.	20 persons with COPD 3 family members to persons with COPD	Social networks offered emotional and practical support but also had potential for conflict with patients' 'hardy' coping style. Patient hardness (characterized by a sense of 'commitment' and 'challenge') promoted a proactive approach to self-management but made some patients less willing to accept support Information-seeking tendencies varied between patients and were sometimes shared with caregivers.	Medium
Gilliam EA et al 2018 USA Ref ⁶⁸	In the context of this trial, qualitatively characterize patient experiences, better understand emergent patient-centered outcomes, and explore behavioral changes in the two intervention groups compared to an education control group.	Semi structured qualitative interviews (sub-study in the trial)	66 persons with COPD	Mind-body interventions including meditative breathing may impact behavior-related neurocognitive and emotional factors that improve self-care management and support positive behavioral changes in patients with COPD	High

Glenister, K et al 2019 Australia Ref ²⁶	To explore patients' experiences of living with, and adapting to, chronic obstructive pulmonary disease (COPD) in the rural context.	Semi-structured interviews	21 persons with COPD Some family carer?	The findings show: internal facilitators (coping strategies; knowledge of when to seek help) and external facilitators (centrality of a known doctor; health team 'going above and beyond' and social supports) and internal/ external barriers to COPD self-management (loss of identity, lack of access and clear communication, sociocultural challenges), which were moderated by feelings of inclusion or isolation in the rural community or 'village'.	Medium
Guo SE & Bruce A 2014 Canada Ref ²⁸	To describe the experiences of patients who are in a pulmonary rehabilitation program and explore the perceptions of both patients and health professionals about what improves effective pulmonary rehabilitation.	Qualitative interviews and focus groups	25 persons with COPD + 7 Health care professionals	Qualitative findings from this study suggest that a patient's adherence to a COPD rehabilitation program can be improved by quickly building up the participant's confidence, promoting tangible results, and by timely recognizing and responding to the issues of readiness and access	Medium
Henoch I et al 2023 Sweden Ref ⁶⁴	To describe how family caregivers and healthcare staff in COPD care experience ICT	Qualitative interview	36 caregivers to persons with COPD 17 health care professionals	The results showed that both family caregivers and staff had limited interest in ICT and stated that it might be better for a new generation but not for themselves.	Medium
Johansson H et al 2019 Sweden Ref ⁶⁵	To identify and describe the symptom burden and its effect on daily life in people with COPD, based on their own lived experiences.	Qualitative interviews	25 persons with COPD in stage III and IV	Persons with COPD in stages III and IV have an altered life caused by the symptom burden. They must struggle with strategies to handle everyday life. There is a need of support from the next of kin and society to facilitate daily living, but this support needs to be well-balanced.	Medium
Johansson H et al 2023 Sweden Ref ⁶⁶	To identify and describe the caregiver burden experienced by next of kin of persons with severe COPD	Qualitative interviews	21 next of kin to persons with COPD	The next of kin experience caregiver burden as changed roles in daily life, they put life on hold and are standing aside. The next of kin need support to manage daily life.	Medium
Johansson H et al 2023b Sweden Ref ⁶⁷	To diverge or converge views of symptom burden, caregiver burden, the need for support, and sense of coherence in persons with chronic obstructive pulmonary disease and their next of kin to gain a deeper and broader knowledge and understanding.	Mixed methods study	112 persons with COPD and 71 next of kin Interviews: 25 persons with COPD + 21 next of kin	There is a difference between estimated symptoms and caregiver burden and experiences expressed in their own words. There is also a defect regarding meaningfulness, comprehensibility, and manageability affecting daily life. Symptoms and caregiver burden, together with the sense of coherence, strengthen the need for support.	Medium
Krag T et al 2023 Denmark Ref ³⁹	To investigate how individuals living with COPD experience different combinations of virtual and in-person care, to help us better understand what aspects are valued and how to best combine elements of these services in future care.	Semi-structured interviews	15 persons with COPD	Medical and emotional support from health care professionals is a key aspect of care for individuals with COPD. Acute treatment with at-home medicine, monitoring one's own condition through technology, and having easy access and close contact with health care professionals familiar to them can promote self-management and well-being, as well as provide a feeling of security.	Medium
Lan X et al 2020 China Ref ³²	To examine self-management behaviors level and discuss the associated factors among chronic obstructive pulmonary disease (COPD) patients	A descriptive instrumental study	124 persons with COPD	Pearson correlation analyses and ANOVA revealed that age, course of disease, education, marital status, family function, subjective support, objective support, and availability of support were positively correlated with overall self-management behaviors Multiple linear regression analyses revealed that subjective support and availability of support significantly predicted self-management behaviors	Medium

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Table I (Continued).

Author, Year, Location	Research Aim	Study Design	Sample Characteristics	Main Findings/ Results	Methodological Quality
Leine M et al 2017 Norway Ref ⁵⁶	To explore chronic obstructive pulmonary disease patients' experiences with a partnership-based nursing practice program in the home setting.	Qualitative study interviews	6 persons with COPD	The findings highlighted to be seen, talked with and understood; healthcare support at home—continuity, practical support and facilitation; and exchange of knowledge. Important was also feeling safe and comforted, and motivation to achieve better health.	Medium
Lundell S et al 2020 Sweden Ref ⁶⁸	To explore how people with COPD experience COPD-related interactions with healthcare professionals in primary care, and how these interactions influence their self-management and how they cope with their disease.	Qualitative interviews GT	13 persons with COPD	Mutually respectful and regular relationships with healthcare professionals, along with a personal positive view of life, empowered and facilitated participants to accept and manage their disease.	Medium
Madawala S et al 2023 Australia Ref ²⁷	Investigate healthcare experiences of patients living independently in the community with COPD who smoked or had recently quit (at most within the last 5 years), seeking care in primary care settings.	Qualitative interviews	13 persons with COPD	Pro-active, empathetic care from general practitioners is desired from patients living with COPD. Stigma and fear of judgement was an important underlying driver of negative care experiences contributing to delayed help seeking from general practitioners	Medium
Marx G et al 2016 Germany Ref ⁴¹	To explore what it means for patients to live with chronic obstructive pulmonary disease (COPD) as an incurable and constantly progressing disease.	Qualitative interviews	17 persons with advanced COPD	To help patients to improve disease awareness, and improving their reduced quality of life, multiprofessional patient-centered and team-centered approach is beneficial. Of importance are psychological support	Medium
McCabe C et al 2014 Ireland Ref ¹⁶	To develop peer based educational, motivational, and health-promoting peer based videos, using behavioral change principles, to support self-management in patients with COPD	Action research Interviews/ focus groups	32 persons with COPD	Findings pointed out relevant areas to behavioral change which included self-management, support, symptoms, knowledge, rehabilitation, and technology. Participants commented that content needed to be specific	Medium
Mi E et al 2018 UK Ref ⁸⁴	Assess agreement between patients and carers on symptoms, and factors associated with disagreement	Prospective, cross-sectional	119 persons with advanced COPD	Overall, agreement between patients and carers was fair to moderate and was poorer for more subjective symptoms. There is a need to encourage open dialogue between patients and carers to promote shared understanding, help patients express themselves and encourage carers to draw attention to symptoms that patients do not report	Medium
Nakken N et al 2016 The Netherlands Ref ⁷²	Investigate differences between male and female partners of patients with COPD regarding their own characteristics and their perceptions of patients' characteristics	Cross-sectional study	188 partners to persons with COPD	Health care providers should pay attention to the needs of all partners of patients with COPD, but female partners in particular.	Medium
Oates GR et al 2019 UK Ref ⁸⁵	Exploring barriers and facilitators of adherence to PR using focus groups with COPD patients to identify potential adherence-promoting strategies.	Mixed methods study	24 persons with COPD	This study identified barriers and facilitators to pulmonary rehabilitation from the perspective of COPD patients. Pointing out health limitations, social support, transportation, financial difficulties, and program features impact ability of patients to attend sessions.	Medium
O'Connell S et al 2021 Ireland Ref ⁴⁷	To explore and describe the self- management support (SMS) preferences of adults with asthma and/or chronic obstructive pulmonary disease (COPD).	Qualitative research Interviews /focus groups	20 persons with COPD and/ or Asthma	Routine support for people with asthma/COPD needs to be comprehensive in addressing the individual patient's challenges	Medium

Paap MSC et al 2014 The Netherlands Ref ⁷³	To identify which domains of HRQoL are most important with respect to COPD, from the patient perspective.	Semi-structured interviews	21 persons with COPD	Important domains of HRQoL for patients with COPD were: physical health (fatigue, physical functioning), social health (instrumental support, ability to participate in social roles and activities, companionship, and emotional support) and coping with COPD.	Medium
Pendonì R et al 2023 Italy Ref ⁴⁹	To explore family caregivers' experiences of contributing to self-care of patients with chronic obstructive pulmonary disease (COPD)	Semi-structured interviews	17 family caregivers of persons with COPD	Family caregivers provided practical and emotional support, and their contribution was essential to improve treatment adherence, to enable the patient to continue living a normal life, and to have access to the healthcare services.	Medium
Poureslami I et al 2017 Canada Ref ²⁹	Explored patient acceptability of "peer supporters" in promoting sustained self-management practices after PR and to assess their perceived self-efficacy to manage their disease.	Qualitative study	28 persons with COPD	The majority of participants considered peer supporters to be good facilitators for motivating ongoing exercise after completing PR.	Medium
Reitzel T et al 2022 Germany Ref ⁴²	To explore and describe the experiences and coping strategies of informal caregivers who deal with this challenging condition.	Semi-structured interviews	13 informal caregiver to persons with COPD	Informal caregivers of patients with chronic breathlessness need support and advice on how to better cope with episodic breathlessness.	Medium
Restrepo JE et al 2022 Colombia Ref ³⁵	To analyze the relationships between mood, perceived social support, and some sociodemographic variables in a sample of Colombian older adults with COPD	A cross-sectional, descriptive, and correlational quantitative non-experimental study	110 persons with COPD	The mood of the older adults was predominantly negative and, in general, there were low levels of perceived social support (except for instrumental support). Statistically significant associations were found between the practice of physical exercise with the level of positive emotional state and instrumental emotional support.	Medium
Sigurgeisdottir J et al 2019 Iceland Ref ⁴³	To explore patients' experiences, self-reported needs, and needs-driven strategies to cope with self-management of COPD.	Qualitative interviews	10 persons with severe COPD	COPD negatively affects patients' physical and psychosocial well-being, family relationships and, social life. Identifying patients' self-reported needs and needs driven strategies can enable clinicians to empower patients by educating them to improve their self-management.	Medium
Skerry L et al 2022 Canada Ref ³⁰	To explore the lived experiences of older Canadian adults with COPD regarding medication adherence and management	Semi-structured interviews	20 elderly persons with COPD	Findings suggested a need for improved continuity of care, disease-related information provision and means of addressing psychosocial needs	Medium
Spitzer KA et al 2020 USA Ref ⁸⁹	To develop an understanding of factors, hinder or facilitate PR participation by interviewing patients.	Qualitative interviews	15 persons with COPD	The results highlight the importance of increasing awareness of PR and building trust between the provider and patients to facilitate initial enrollment.	Medium
Strang S et al 2018 Sweden Ref ⁶⁹	To describe perceptions of healthcare support to informal caregivers, both from the family caregiver's and the staff's perspective.	Semi-structured interviews	54 persons with severe COPD 36 informal caregivers of persons with severe COPD 17 healthcare professionals	The findings suggest that strategies and routines for caregiver support, emotional, practical and informational) including communication skills among the staff, should be developed, to move toward the family perspective advocated in palliative- and nursing family care.	Medium

(Continued)

Table 1 (Continued).

Author, Year, Location	Research Aim	Study Design	Sample Characteristics	Main Findings/ Results	Methodological Quality
Strang S et al 2018 b Sweden Ref ⁷⁰	To obtain detailed knowledge about people's experiences, for example, transitions in relationships, responsibility, and possible changes in communication, caused by the illness	Semi-structured interviews	35 next of kin to persons with COPD	Being a family caregiver is a burdensome and complex situation. Besides providing practical help, the family caregiver needs to support the ill person. Healthcare staff must identify the needs of the family caregivers. A family caregiver who feels acknowledged and confident can support their severely ill family member.	Medium
Suresh M et al 2022 USA Ref ⁹⁰	To explore the experiences, roles in care seeking, and needs of caregivers during COPD exacerbations	Semi-structured interviews	24 caregivers of persons with COPD	Findings shows that caregivers reported continuously monitoring changes in patient's symptom, and emotional reaction evoked by exacerbations. There were disagreements with their patient in interpreting symptoms and determining the need for care seeking and the caregivers noted uncertainty regarding their roles and responsibilities in pursuing care. The caregiver expressed their need for additional information and support.	Medium
Tumilty E et al 2020 Portugal Ref ⁶⁰	To understand how patients with severe COPD living in the Southern Health Region (Otago and Southland) experience and cope with the condition.	Semi -structured interviews	23 persons with severe COPD	Patients' accounts of living with severe COPD revealed four themes: loss, adaptation, isolation and social support.	Medium
Turnier L et al 2021 USA Ref ⁹¹	To explore the association between perceived social support and COPD outcomes and to determine whether the associations are mediated by depressive symptoms.	Questionnaire cross-sectional and longitudinal analyses	1779 persons with COPD	Higher social support was associated with better COPD outcomes across several measures of morbidity including quality of life, respiratory symptoms, and functional status.	Medium
Utens CM et al 2014 The Netherlands Ref ⁷⁴	Informal caregiver strain, satisfaction, and preferences for place of treatment with a community-based hospital-at-homes scheme for COPD exacerbations	randomized controlled trial	139 persons with COPD 124 next of kin	There were no differences in caregiver strain between the community-based hospital-at-home scheme and usual hospital care. Most caregivers were satisfied with the treatment.	High
Wang et al 2018 China Ref ³³	To describe the experiences of patients participating in a health coaching self-management program for patients with COPD in People's Republic of China.	Qualitative study	20 persons with COPD	The participants experiences were expressed as gaining insight into the importance of knowledge and personal responsibilities in the management of COPD, feeling supported by the program, and iterative interactions between patients and health care professionals.	Medium
Yi M et al 2021 China Ref ³⁴	To explicitly explore whether social support and negative coping styles play the chain mediating roles in the relationship between the caregiving burden of caregivers of COPD patients and their health-related quality of life.	Multicenter cross-sectional survey	201 caregivers to persons with COPD	The result showed that caregiving burden could directly and negatively predict quality of life, and also predict quality of life through the chain mediation of social support and negative coping styles. Therefore, healthcare professionals should provide targeted guidance to caregivers with the help of social support and interventions that regulate negative coping styles.	Medium
Zakrisson et al 2020 Sweden Ref ⁷¹	To investigate the effects on the quality of care of the Patient Report Informing Self-Management Support (PRISMS) form compared with usual care among patients with chronic obstructive pulmonary disease (COPD) consulting a COPD nurse in primary health care	A multicenter randomized controlled trial with a post-test design	94 persons with COPD = I-group 108 persons with COPD. = C-group	The PRISMS form improved patient satisfaction with quality of care regarding personal attention, which is an important factor in patient participation and improving relationships and communication.	Medium

areas, including physical training, health education, psychological support, and motivational communication,^{28,40,56,82} while also facilitating peer support.^{27,30,52,88} Personal commitment involves healthcare professionals who genuinely care for their patients, acknowledging individuals with diseases such as COPD. This means listening to patients and allowing them to share their stories without facing judgment. It's not merely about conducting medical tests or checks; it's about fostering engagement and providing meaningful assistance.^{29,47,61} To provide the best possible support, healthcare professionals should inquire about psychological issues.⁷⁹ Holistic support throughout the disease process is essential to good primary care treatment. There is a need for reformed services that better reflect patients' needs through improved communication between professionals and patients, facilitating better access to services.⁸⁰

Support is Requested by Next of Kin to Persons with COPD

Caregivers for individuals with COPD are often their next of kin.^{50,84} More than half of those diagnosed with COPD are married or in a partnership, 75% live with others, and 90% report having a family caregiver.⁸⁷ These caregivers often find themselves in a challenging situation and may lack adequate support. Most information and interventions tend to focus on the individuals affected by the disease, rather than directly addressing the needs of their caregivers.^{53,81} Consequently, family members of people with COPD require support that includes knowledge about the disease, its symptoms, and effective management strategies.^{42,49,54,58,75} Next of kin feels overwhelmed by all the symptoms and the responsibility of assessing the affected individual's needs while also handling practical and financial tasks and assisting with medication. Next of kin feel unseen and unsupported by the healthcare system.^{27,37,39,45,62,63,68} The next of kin wishes to be kept informed about the status of the person with COPD, as they want to be involved in the healthcare and planning process.⁶⁶ However, support ratings from family members and financial assistance tend to be lower, indicating a potential lack of support and the economic impact of being the next of kin to someone with severe COPD.⁶⁷ These concerns can lead to caregiver burden. Research shows that caregiver burden is linked to the condition of the person with COPD; specifically, caregiver burden scores tend to decrease when the patient's self-efficacy score increases. The patient's self-efficacy is higher when their social support score is elevated, which often comes from support provided by the next of kin.⁵⁰ Although the emotional states of caregivers did not change significantly due to the intervention, there were considerable improvements in their caregiving burden, CADI global score, and the subscales related to reactions to caregiving, physical demands of caring, and vague family support.⁷⁵ The burden of caregiving negatively impacts social support; specifically, a higher caregiving burden significantly affects caregivers' overall quality of life.³⁴

Next of kin need support, which is best provided by recognizing and addressing their burden.⁷⁹ A prerequisite for providing support is that caregivers acknowledge the needs of relatives, especially female relatives.⁷³ It is evident that caregivers often receive less support than they require when they seek help from health professionals.⁴⁸ While healthcare professionals sometimes provide the support caregivers request through designated contact persons, this assistance only sometimes meets their needs. Additionally, some caregivers have connected with family caregiver associations, which have offered them valuable information, facilitated access to one another, and allowed them to share their experiences as family caregivers.⁶⁴

The support needed by caregivers differs from the support provided by healthcare staff. Informal caregivers seek emotional, practical, and informational support, while healthcare professionals primarily focus on providing information. As a result, caregivers often feel neglected.^{69,70} Home care support can alleviate the burden on relatives by reducing the need for travel. However, caregivers want more assistance regarding the symptoms and management of respiratory difficulties affecting their loved ones.⁷⁴ While professional home care is primarily aimed at the patient, it often does not address the needs of informal caregivers.⁵³ Caregivers also express a desire for improved communication between hospitals and home care services, as well as better planning for discharge procedures. They feel it is crucial to be included in the healthcare process and recognized for their contributions beyond their caregiving roles.⁴⁸

Many individuals desired informal support from friends, particularly those in similar situations who could offer valuable peer support.⁴⁸ They believed that support and information available through the Internet could foster a sense of community, and support groups were generally viewed positively.⁴⁶

Families and friends played an important role in supporting many caregivers by expressing understanding and listening to their frustrations and concerns. Caregivers also felt a sense of security when they could share responsibilities for the person with COPD) with others, including home care workers, healthcare professionals, or neighbors.⁶²

Support Accessible and Valued by Persons with COPD and Their Next of Kin

Healthcare professionals should provide advice, information, and guidance to help patients reframe their expectations, acknowledge their current situation, and enhance their autonomy.⁷⁷ When the nurse provides concrete advice, persons with COPD only sometimes perceive that they have received concrete advice due to communication deficiencies.³¹ Family members/next of kin expressed satisfaction with the support provided, both in hospitals and at home.⁷⁴ However, they needed more concrete advice.³¹ Relatives desire more information about symptoms and treatment to feel secure and safe.^{55,75} Information was preferred through interaction rather than instruction²⁸ and in the right amount and level.⁸³

The involvement of individuals with COPD and their families is crucial in discussions to provide optimal support and develop effective interventions.⁸⁴ Next of kin who are present and support in assessing symptoms and acting experience being caught in a dilemma between the affected persons, themselves, and healthcare, and therefore need additional support in these situations.⁵³ The family members participating in training programs with the affected individual gain a deeper understanding of the disease and its symptoms, enhancing their ability to provide support.⁵⁷

A multidisciplinary team and collaboration between all levels of care and society are crucial for optimal support.⁷⁹ Therefore, the problems faced by those affected should be considered in healthcare planning and resource allocation to provide the best possible support.⁸⁰ Carers often face challenges when coordinating with healthcare services. They frequently find the healthcare system to be unpredictable and inaccessible. Many carers feel that healthcare professionals are impersonal and, at times, demeaning. They believe their concerns are often dismissed, and unresolved issues are overlooked.⁶² Additionally, health professionals only sometimes recognize carers as experts or valuable resources. In contrast, carers strongly desire to be informed and involved in decisions regarding caring for individuals with COPD. Typically, people with COPD spend a significant amount of time updating their healthcare providers about their condition, which leaves them with little opportunity to discuss what they consider essential in their daily lives.³⁸

Home-based care and rehabilitation are alternatives to outpatient visits and hospitalization that support persons with COPD in participating in and benefiting from their training and care.⁴⁰ Receiving professional assistance at home not only provided help and relief but also necessitated adjusting to the presence of new individuals in their space multiple times a day. This situation disrupted the couple's privacy and the natural rhythm of their daily lives.⁵³

Support programs can be beneficial as they provide insight into how others manage their illness, offer social contacts, and promote relationships with next of kin.⁸⁸ Participating in a training program provides support through interaction with others in similar situations^{52,55,85} and encourages adherence while avoiding disrupting the group dynamic. Training interventions should be flexible and accessible, as transportation can be a barrier.⁸⁵ Supervision during training is perceived as an essential support function.⁵² They should also be family-focused and foster patient engagement to provide the best support.⁸⁵ Support from fellow patients in rehabilitation increases adherence and continuity.²⁹ When rehabilitation involves relatives, participation increases more than fivefold.³¹

Support programs help manage the disease by providing knowledge about its progression, symptoms, severity, and rehabilitation.^{28,33} Various e-health tools can be supportive.⁸² Having a clear healthcare plan is essential.⁷⁹ E-health tools empower affected individuals to control and manage their disease.⁸²

Internet-based knowledge sources increase understanding of the disease, its management, treatment, and prognosis.³³ Support and training via digital platforms increase flexibility, participation opportunities, and cost-effectiveness, leading to increased engagement.⁵² Coaching via IT or telephone resulted in a lack of personal contact, demonstrating that the physical distance between staff and patients hindered relationship-building. Participants expressed a desire for face-to-face meetings with professionals.⁶¹

Relatives are essential in supporting training by providing information, advice, practical assistance with various tasks, and emotional support. Additionally, face-to-face contact with healthcare professionals proved beneficial, as it helped in becoming familiar with the system.⁷⁸ Information and knowledge via the internet were problematic because computer literacy was lacking.⁶⁴

Additionally, a robot can support persons by remembering medication and reminding them of training.⁵¹ Persons with good healthcare contact see no need for additional support via digital platforms.⁶¹

Confidence in Synthesized Results

Since most of the studies included in the review were qualitative and mixed methods studies, it seemed relevant to assess the level of confidence in each category using the Grading of Recommendations Assessment, Development, and Evaluation–Confidence in Evidence from Reviews of Qualitative Research (GRADE-CERQual).⁹³ CERQual has previously been applied to more descriptive-level review findings in syntheses.

GRADE-CERQual comprises four domains that assess uncertainties in the data: methodological limitations, relevance, adequacy of data, and coherence, and aims to evaluate and describe through a transparent procedure how much confidence/reliability there is in the findings. Therefore, an overall confidence rating of “high”, “moderate”, “low”, or “very low” was assigned to each category, considering each of the four GRADE CERQual components. All categories were judged to have a moderate to high confidence level (Table 2). This judgement was because they were based on rich material where the context was relevant, the data had coherence, and there were only minor methodological limitations. All studies with methodological flaws were not included in the review.

Table 2 Summary of the Results and Its Reliability

Category	Content, Articles Contributing to the Categories and Number of Participants	Scientific Support According to CERQual
Support in various forms is crucial for persons with COPD	Social support is crucial in self-management and managing daily life. Persons with COPD receive support from different sources, but the primary source is spouses/next of kin as caregivers. They are often described as those providing practical or emotional forms of support. Emotional support impacts physical and basic activities. Adequate support includes addressing physical needs, judging symptoms, assisting with medication, communicating, and assisting with activities of daily living. Healthcare professionals were often viewed as providing informational and educational support. The persons with COPD requested that healthcare professionals inquire about psychological issues to provide the best possible support. ^{25–33,35,41,43–47,49,54,56,57,59,60,63,65–68,70,71,73,75–80,82,83,85–92} n= 4451	High reliability Minor methodological flaws High coherence: 56 included studies that demonstrate underlying data contributing to this category. Sufficient data, a total of 13,894 participants, were included in the studies. Each study had collected data from enough participants to present abundant material. Relevance: the context is consistent with the research question. 9 (16%) of the 56 studies were conducted in Sweden.
Support is requested by next of kin to persons with COPD	Mainly, there are next of kin acting as caregivers. Next of kin faces a demanding situation and lack of support. Information and interventions are directed towards the affected persons, including the next of kin, not directly addressed. Next of kin feels overwhelmed by all the symptoms and the responsibility of assessing the affected individual's needs while also handling practical and financial tasks and assisting with medication. Next of kin feels unseen and unsupported by the healthcare system. The burden of caregiving has a negative direct effect on social support; a higher burden of care for caregivers, in turn, significantly affects their level of quality of life. The support the caregivers requested was provided by healthcare professionals in different instances, that is, through contact persons within the healthcare profession, but only sometimes fulfilling the needs. ^{6,29,32,37,39,42,45,48–50,53,54,57,58,61,63,64,66–70,72,74,75,81,84,87} n= 1757	Moderate reliability Minor methodological flaw High coherence: 28 included studies show underlying data contributing to this category. Sufficient data, a total of 1839 participants were included in the studies. Each study had collected data from enough participants to present abundant material. Relevance, the context is consistent with the research question.7 (25%) of the 28 studies were conducted in Sweden
Support accessible and valued by persons with COPD and their next of kin	The problems faced by those with COPD should be considered in healthcare planning and resource allocation to provide the best possible support. Carers often became frustrated by the difficulties that arose when coordinating with healthcare. Carers sometimes experience health care as unpredictable and inaccessible. As carers, they felt that healthcare professionals were impersonal and sometimes demeaning. Healthcare professionals should give advice, information, and guidance and help patients reframe their expectations, acknowledge their current situation, and enhance autonomy. ^{28,29,31,33,37,38,40,51–53, 55,57,61,62,71,74,75,77,79,80,82,85,88} n=1346	High reliability Minor methodological flaws High coherence, 2 included studies demonstrate underlying data contributing to this category. Sufficient data, a total of 1589 participants were included in the studies. Each study had collected data from enough participants to present abundant material. Relevance, the context is consistent with the research question.3 (0.1%) of the 24 studies were conducted in Sweden

Discussion

This systematic integrative literature review identifies key elements that could serve as a foundation for developing an intervention involving individuals with COPD and their next of kin. The findings highlight how care for individuals with COPD is currently delivered and what aspects it emphasizes. It is important to recognize that the next of kin are often taken for granted and need to be consistently acknowledged in the care process. This review addresses some of the existing knowledge gaps and can serve as a starting point for creating necessary interventions. Current interventions primarily target the person with COPD, and few interventions involve caregivers but do not directly address caregivers with support to provide care and be emotional support for the person with COPD.¹² Caring for a relative with COPD can be a stressful experience. The unpredictable nature of the disease, particularly the threat of severe and unexpected breathlessness, often leads to emotional distress for family caregivers. Many carers feel frustrated by the lack of comprehensive explanations from health professionals regarding the disease's progression and management strategies, leaving them unprepared for their caregiving role. Additionally, family carers frequently report a lack of emotional support and respite services, which are crucial for enabling them to continue providing care throughout the course of the disease.

The relationship between the family caregiver and the person with COPD is also affected; the affected persons' breathlessness can hinder communication, isolating the patient from their spouse and family. Spouses have reported that feelings of intimacy and friendship with their partner diminish, leading to a sense of loss of personal identity and motivation to care. Nevertheless, caregivers persist in their roles, driven by a sense of duty influenced by marital vows and societal expectations.

A review by Cruz et al⁹⁴ highlighted the negative impacts of caring for a person with COPD on their next of kin, categorizing these impacts into five themes: physical health, emotional health, social health, relational health, and financial/employment impacts. Physical health is compromised, as caregiving is demanding and leads to fatigue. Constant supervision and assistance contribute to social isolation since the person with COPD becomes increasingly dependent. These findings align with our own observations regarding health, emotional, and social aspects of caregiving. Furthermore, Zakrisson et al⁹⁵ discovered that caregivers experienced relief from their burdens when included in a pulmonary rehabilitation session. During these sessions, they learned strategies to enhance their own well-being and received support from others facing similar challenges. Supportive interventions can improve caregivers' coping skills, boost their self-efficacy in managing patients' symptoms, and reduce emotional distress.⁹⁶ Since most interventions have specific outcomes tailored to particular domains, it is essential to customize these interventions to address the unique needs and challenges of family carers.⁹⁷

Despite the significant burden placed on informal caregivers, formal support for them is largely inadequate.¹² Few studies have involved the patient-caregiver dyad in educational and self-management sessions during pulmonary rehabilitation, leading to conflicting results.^{12,98,99} These interventions primarily focused on enhancing caregivers' understanding of the disease and providing coping strategies to support patients with COPD. However, it's important to recognize that informal caregivers are individuals who also require personalized interventions to improve their physical and psychological well-being.

In the Nordic countries, the healthcare system and care structure generally expect next of kin to participate in the care of the affected individual.¹⁰⁰ In general, the efforts made by next of kin in ordinary housing are two to three times greater than those provided by formal care.¹⁰¹ According to the Swedish National Board of Health and Welfare (2014),¹⁰² one in four people in Sweden over the age of 55 provides care for a family member or loved one. This responsibility can lead to a decreased quality of life due to high stress levels, which can affect one's health, as evidenced by this study. A study from Ireland shows that next of kin lack or receive inadequate support as caregivers, which confirms our study's findings regarding family members' involvement in the role of informal caregivers. There are strategies to support next of kin, but there is difficulty in implementing this support in practice.¹⁰³

A recent study researched and evaluated a nurse-led supportive care service for patients with chronic obstructive pulmonary disease (COPD). The key areas of focus included symptom management, advance care planning, home visits,

expert advice, continuity of care, trust-building, compassion, and support for caregivers. These areas align with our findings.

The study also provided suggestions for improvements. Patients with COPD value receiving care in their homes, and both patients and their caregivers appreciate the opportunity to participate in nurse-led advance care planning. It is essential to consider the experiences of patients and caregivers when developing healthcare services that effectively address the needs of those living with COPD.¹⁰⁴ But still, the focus is on managing and coping with COPD; the support is still sparse regarding the need for caregivers.

Several studies in our review focused on COPD treatment, physical activity, and how COPD affects the person with COPD. The support supplied to the person with COPD needs to be developed with more focus on emotional support. Emotional support has been proven to affect the frequency of depression in persons with COPD and increase the ability for physical activity, which in turn enhances well-being. Several studies in our review highlight the need for support through permanent care contact with the healthcare system to reduce readmission. One model that may be suitable is the Transitional Care Model (TCM).¹⁰⁵ This TCM model has been developed, has documented positive effects on the sufferer's health, and has also been shown to reduce hospital readmission.^{106,107} The transitional care model is designed to provide comprehensive care for chronically ill patients, both in the hospital and continuing at home. For individuals with chronic diseases or complex treatment plans, this model emphasizes a care approach that prioritizes continuity of care, with the goals of prevention and avoiding complications related to their conditions. Additionally, the model involves patients and their families in the care process, coordinating closely with physicians. This active engagement is essential for improving and promoting the health of individuals with chronic illnesses.¹⁰⁸ According to this review,¹⁰⁸ the benefits of TCM include reduced re-hospitalization time, increased lifespan, enhanced physical performance and quality of life, greater patient satisfaction, decreased repeated hospital visits, and lower healthcare costs. Nevertheless, once again, the caregiver is involved as a team member, but their well-being is disregarded.

The challenge is thus finding alternative working methods to benefit the persons with COPD and their relatives. This double perspective aligns with "Primary Care Reform",^{109–111} based on finding effective collaboration methods, such as through multi-professional teams, reinforced discharge procedures, and care coordinators. A person with COPD, along with their next of kin, can benefit from education during care transitions. While this practice is less common in Sweden, it is implemented in many other countries. Research suggests that the most effective interventions are comprehensive and include multiple components. This approach ensures that the discharge process involves both the affected individuals and their next of kin, providing them with education for self-care and making the overall care more person-centered and efficient.¹⁰⁶

This review identified significant gaps in knowledge on support for those with COPD and their next of kin/caregivers. Support, within the broader definition, includes help and understanding from a physical, psychological, and social perspective. It should be addressed on equal terms to persons with COPD and their carers. The limitations of existing literature on support for COPD patients underscore the necessity for additional research.

Strengths and Limitations

This systematic review has several strengths. To our knowledge, it is the first comprehensive review that synthesizes empirical evidence on the support provided to people with COPD and their families. Additionally, the review includes studies with various methodological approaches, which enriches the data summary and synthesis and strengthens the overall findings. However, some limitations should be acknowledged. The authors published three studies in the review, but all assessments of all included articles were treated according to the different tools to avoid bias. Three different tools from The Joanna Briggs Institute^{19–21} were used to assess quality. These are sweeping (broad) judgment tools for disparate methodology and data, which may affect the quality assessment.

Therefore, the quality was only set to Low, Medium and High. Those with Low assessment were excluded. Another limitation of the review is that it only included studies published in English and did not consider grey literature, which may have resulted in the exclusion of relevant studies. The findings originate from a variety of countries, and although they reflect a diverse population, they may not be fully transferable or generalizable to all the represented countries, or to those not directly included in the study.

Implications for Research and Practice and Directions for Future Research

This review highlights the significant impact that COPD has on the daily lives of individuals diagnosed with the condition, as well as on their family members. It emphasizes the need to develop a comprehensive lung program that supports patients and their caregivers to enhance their understanding of the disease and improve self-management. This means acknowledging everyone involved and using their knowledge, abilities, and experience to strengthen self-care activities. Further research is needed to examine the available support types and how they affect individuals with COPD and their families. Exploring and measuring the nature of the assistance provided and how it is received is essential.

Conclusions

In conclusion, this systematic integrative literature review identified key elements regarding support that could serve as a foundation for developing an intervention involving individuals with COPD and their next of kin, addressing their needs. Further research is necessary to explore the impact of support, assistance, and understanding from physical, psychological, and social perspectives within the daily lives of both those with COPD and their caregivers.

Acknowledgments

Thanks to Jenny Aspling Rydgren of the Medical Library at Linköping University, who provided valuable input and feedback on the search strategy.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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