# Palliative care provision for patients with advanced chronic obstructive pulmonary disease: A systematic integrative literature review

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# Abstract

Although chronic obstructive pulmonary disease (COPD) is recognized as being a life-limiting condition with palliative care needs, palliative care provision is seldom implemented. The disease unpredictability, the misconceptions about palliative care being only for people with cancer, and only relevant in the last days of life, prevent a timely integrated care plan. This systematic review aimed to explore how palliative care is provided in advanced COPD and to identify elements defining integrated palliative care.

Eight databases, including MEDLINE, EMBASE and CINAHL, were searched using a comprehensive search strategy to identify studies on palliative care provision in advanced COPD, published from January 1, 1960 to November 30, 2017. Citation tracking and evaluation of trial registers were also performed. Study quality was assessed with a critical appraisal tool for both qualitative and quantitative data.

Of the 458 titles, 24 were eligible for inclusion. Experiences about advanced COPD, palliative care timing, service delivery and palliative care integration emerged as main themes, defining a developing taxonomy for palliative care provision in advanced COPD. This taxonomy involves different levels of care provision and integrated care is the last step of this dynamic process. Furthermore, palliative care involvement, holistic needs' assessment and management and advance care planning have been identified as elements of integrated care.

This literature review identified elements that could be used to develop a taxonomy of palliative care delivery in advanced COPD. Further research is needed to improve our understanding on palliative care provision in advanced COPD.

## Introduction

Worldwide COPD is a leading cause of morbidity and mortality in adults.[1] A progressive decline in overall function, patient's independence and health-related quality of life is well-described in this particular healthcare population.[2] Disease progression in COPD is correlated with an increased symptom burden.[3,4] The high prevalence of physical symptoms and psychological distress in advanced COPD is comparable with or worse than the symptom burden reported in the lung cancer population.[5] Although COPD is recognized as being a life-limiting condition with palliative care needs, palliative care provision is seldom implemented in this population.[6] The disease unpredictability, the misconceptions about palliative care being only for people with cancer, and only relevant in the last days of life, prevent a timely integrated care plan for patients with advanced COPD.[7]

Care integration is not consistently defined in the available literature. Depending on care settings, healthcare providers and consumers, the term "integrated" defines different approaches to care delivery.[8,9] Different options for palliative care integration in standard care have been proposed.[10,11] Coordination of services and improved communication between healthcare professionals, patients and informal caregivers have been studied.[12-14] Siouta[15,16] developed a novel definition of integrated palliative care, linking aspects identified in the literature and agreed through consensus by palliative care experts: "Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers (paid and unpaid)".

However, the question on how to integrate palliative care in the management of advanced COPD remains open.[17] Stakeholders have different viewpoints on palliative care itself and on how to integrate it within disease-directed therapies.[18] Bridging the theory practice gap may generate practical knowledge on palliative care approaches within respiratory medicine, which in turn may lead to an organizational change for the researched community.[19] Therefore, it is pivotal to synthesize the available research findings on palliative care provision in advanced COPD to develop theories about care delivery and inform practice.

This literature review focused on answering the following questions: "How is palliative care provided in advanced COPD and what elements define integrated care in this population?" Patients' and services' outcomes on palliative care provision for this population and the application and practices of palliative care integration in advanced COPD services have been explored.

# Methods

## Search strategy and study selection criteria

For this systematic integrative review, we used a comprehensive search strategy to identify relevant studies. Integrative reviews allow a systematic analysis and summary of both experimental and non-experimental research and can precisely represent the state of the current research literature on the topic.[20] This integrative review followed the conceptual model described by Whittemore and Knapf, consisting of five stages: problem identification, literature search, evaluation of data, data analysis and interpretation and presentation of the results.[21] No language restrictions were applied on searches. We searched the following eight academic databases from January 1, 1960 to June 30, 2017: MEDLINE, EMBASE, CENTRAL, AMED, CINAHL, DARE, HSRProj and OpenGrey. The chosen time period is consistent with the first available publication on definitions of COPD and foundation for the current classification, which was pivotal as inclusion criteria for this review.[22]

The accuracy of the selected terms was tested during a pilot search. The use of synonyms, free text term and Medical Subject Heading (MeSH) led to the proposed key terms that were used for the database search. These terms are described in **Appendix 1**. Boolean operators ("OR", "AND") and truncation tools were used to broaden and narrow the search when considered necessary. Furthermore, systematic reviews identified by the electronic bibliographic databases' search were checked to verify that all relevant papers meeting the selection criteria have been included in the literature review (see **Appendix 2**). International guidelines on care provision for COPD were consulted to identify references related to empirical research. All included papers were citation tracked to identify additional papers and grey literature was searched looking for unpublished dissertations or masters theses. Inclusion and exclusion criteria are listed in **Table 1**. Since no restrictions on study designs were applied, any type of study design could potentially be included in the review (see **Table 2** for included studies and their design). TFS and AR independently screened the 368 titles from the search. Disagreements were resolved by discussion and inter-reviewer agreement for the abstract screening was 100% after reconciliation.

## Data extraction and quality assessment

Data was extracted by two independent reviewers (TFS and AR) and any disagreement was resolved by discussion. A duly created data extraction form was used and electronically managed (MS Excel Template). Theoretical background, research question, aims, study designs, methods of data collection and analysis and key themes identified were among all variables extracted from the included papers.

Study quality assessment was performed independently by two reviewers (TFS and AR) using the checklist from Hawker et al. for evidence appraisal of both qualitative and quantitative studies.[23] Scores < 30 were considered of low quality and were excluded from the literature review. This benchmark was chosen according to the scoring system defined by the quality appraisal checklist, where items were defined with a scoring scale from one (very poor) to four (good).

### Data analysis

Data analysis followed a four-step process: data reduction, data display, data comparison and conclusion drawing. [24] Emerging themes about experiences of living with advanced COPD, about how palliative care is provided and which elements could play an important role in palliative care integration in this population were collected for each study.

### Role of the funding source

There was no funding source for this study.

## Results

**Figure 1** shows the study selection process. Out of 458 records retrieved through comprehensive search, 368 records were screened for eligibility, with 24 papers included in the integrative review. The selected articles were published between 2004 and 2017. Of these papers, 10 adopted a qualitative approach, 11 adopted a quantitative approach, two were mixed-methods studies and one was an action research study. Sample sizes ranged from eight to 88 participants for qualitative studies and 36 to 2405 participants for quantitative studies. A summary of all included studies is presented in **Table 2**. The integrated data are discussed under four main themes: 1) Experiences and perceptions about living with advanced COPD and palliative care provision, 2) Palliative care timing 3) Service delivery and 4) Models of care integration in advanced COPD. An overview of the identified themes is presented in **Table 3**.

### 1. Experiences and perceptions about living with advanced COPD and palliative care provision

Exploring the needs and views of patients, informal caregivers and healthcare professionals about living with advanced COPD and the role of palliative care provision has been the research aim and focus of several published papers.[25-28]

### *High symptom burden and holistic assessment of needs*

Most papers reported that advanced COPD patients present with an elevated symptom burden.[29] Schroedl and colleagues conducted a retrospective case series study on patients with advanced COPD attending a palliative care clinic in the United States. Their results confirmed high symptom prevalence among COPD patients, which had not been previously assessed and treated in a systematic manner.[30]

### *COPD as a "way of life"*

As previously described, patients with advanced COPD describe an elevated symptom burden, but physical, psychosocial and existential issues are often underreported, because COPD is less commonly considered as a life-limiting illness.[27] Landers and colleagues reported that patients and informal caregivers perceive advanced COPD as a *way of life*, thus considering the progressive decline and the functional impairment as part of a life with the disease.[31] They adjust to a progressive worsening of symptoms over months and years. Therefore, according to the authors, misconceptions around the relevance of palliative care in the disease trajectory are frequent, among both patients and their families and healthcare professionals.[32]

### *Need for enhanced communication (advance care planning, end-of-life care)*

Hayle and colleagues evaluated the experiences of patients with advanced COPD accessing specialist palliative care.[28] Open and honest communication between patients, their families and healthcare professionals about diseases prognosis and time limitation prompted a better acceptance of palliative care referral and discussions on advance care planning and end-of-life issues, acknowledging patients' values and wishes for the forthcoming declining disease trajectory.

## **2. Palliative care timing**

As previously described, patients and informal caregivers perceive progressive decline in health as part of living with the disease.[31] Therefore, the timing of palliative care provision in COPD is difficult to establish.[25] In their study, Cawley and colleagues interviewed 52 patients, informal caregivers and healthcare professionals to identify events in the disease trajectory which could act as trigger for palliative care provision.[26] All participants identified increasing carer burden, progressive decline of global functions and hospitalisation for acute exacerbations as milestones in disease progression.

Duenk and colleagues tried to identify specific criteria that can foster the initiation of a timely palliative care approach.[34] In their survey study, they explored the views of 256 pulmonologists in the Netherlands on palliative care provision for patients with COPD. The majority of participants stated that many different criteria to identify patients who would benefit from a palliative care provision were used, but no consensus could be determined on which specific criteria may indicate a timely palliative care initiation. These conclusions were supported by Partridge and colleagues, who conducted a similar survey among 107 respiratory care physicians in the UK.[35]

Spence and colleagues conducted interviews and focus groups with 23 health and social care professionals, exploring their perceptions of barriers faced by healthcare professionals to deliver palliative care.[33] They concluded that among several interventions that may improve palliative care provision it is important to systematically offer focused education and training on communication skills to healthcare professionals who are involved with advanced COPD. Beernaert and colleagues had the same conclusion in their retrospective, population-based study within a general practitioners' network.[36] They collected data on deceased patients and assessed timing of referral to palliative care services. Patients with COPD were less likely to be referred to palliative care services than cancer patients and if referred, experienced a late referral, close to death. The authors underlined the importance of training general practitioners in delivering high quality palliative care, while being supported by specialist palliative care teams and respiratory care physicians for more complex cases.

## 3. Service delivery

Different models of palliative care service provision for patients with advanced COPD have been studied. Bruera and Hui have summarised three different care provision models in a cancer setting, but similar approaches have been described in advanced COPD services.[37-40] In the "Solo Practice Model" the treating physician (general practitioner or specialist) provides the entirety of care, including general palliative care. A step towards increased collaboration is proposed in the "Congress Practice Model", where the treating physician refers the patient for all supportive care issues to different healthcare professionals. Finally, in the "Integrated Care Model", continuity of care is fostered through a palliative care team approach, including all healthcare professionals involved in a patient's care.[37]

### *The "Solo Practice Model"*

Buxton and colleagues conducted an electronic web-survey across 239 hospital units in the UK assessing current and planned palliative care provision for advanced COPD.[38] They described poor palliative care provision and highlighted the role of primary healthcare providers in delivering palliative care. The authors suggest that the primary care team should be confident with general palliative care approaches and care models should empower healthcare professionals who provide support for COPD patients.

*The "Congress Practice Model"*

Buckingham and colleagues assessed the feasibility of a nurse-led intervention to explore holistic needs in patients with advanced COPD as part of a palliative care approach.[41] Although the intervention proved to be feasible, it emerged that it overlapped with existing services. They concluded that referrals to various healthcare professionals for supportive care issues may result in service delivery fragmentation, which is reported as burdensome by patients and their informal caregivers.[37]

## 4. Models of care integration in advanced COPD

The development of an integrated care strategy can be initiated by patients and caregivers' needs.[27] Crawford and colleagues explored patients, informal caregivers and healthcare professionals' views on palliative care provision in COPD and assessed service availability and accessibility. A patient-centered coordinated care model was proposed, fostering the integration of a multidisciplinary palliative approach within standard care.[25] Recommendations to promote care integration included an holistic needs' assessment, discussions on advance care planning and the definition of the interface between primary healthcare providers and specialist palliative care team.

Knowledge on the possibility of team-work with specialized palliative care and care coordination is frequently lacking. Strang and colleagues described in their web-survey among 93 respiratory care physicians, that less than half of the respondents were aware of palliative care service development within their own institutions. [42] The authors suggested healthcare policy makers and patient's organizations involvement in raising awareness on palliative care provision in COPD, both for the public and for healthcare professionals.[28,36] Goodridge and colleagues held a consensus meeting with key stakeholders (healthcare professionals, patients and informal caregivers) on how to provide end-of-life care for patients with advanced COPD.[43] They stressed the importance of continuity of direct care providers and access to a multidisciplinary team for optimal end-of-life care. Furthermore, as described by Hynes and colleagues in their action research study, the development of integrated care requires a fundamental organizational change.[44]

Continuity of care and organizational changes were discussed through models of integrated palliative care in advanced COPD which explored the role of a care-coordinator. [29,45] Burgess and colleagues explored service availability and accessibility through interviews and focus groups with patients, informal caregivers and healthcare professionals.[45] Elkington and colleagues conducted semi-structured interviews with bereaved relatives, trying to capture the experiences of the last year of life in COPD.[29] Both studies promoted a patient-centred model of care for advanced COPD, supporting a structured multidisciplinary approach in each care setting. They identified healthcare professionals that could act as care-coordinator for these patients. Care-coordinator could ensure patient-centred care, while guaranteeing continuing, appropriate and accessible palliative care. The importance of a care-coordinator is also mentioned by Epiphaniou and colleagues.[39] In their longitudinal qualitative study, they explored the experiences in coordinating care among patients with COPD and lung cancer. COPD patients experienced reduced access to a keyworker in home care settings compared to cancer patients. Moreover, the authors described less access to multidisciplinary services of advanced COPD patients in comparison to their oncological counterparts.

As previously debated, continuity of care between involved healthcare professionals is one of the main goals of providing integrated care services.[47] The evaluation of integrated palliative care provision in advanced COPD has been the research aim of several published studies.[48,49] Nonetheless, heterogeneity among studied interventions is important.[40] For this reason, it is pivotal to employ identification criteria which describe integrated palliative care, supporting service development and outcomes evaluation. An overview of included studies exploring integrated palliative care is presented in **Table 4**. Aiken and colleagues determined the feasibility of a homecare-based palliative care intervention in a randomized controlled trial. [48] 100 patients were followed at home by a multidisciplinary team, led by a registered nurse case manager and both the primary care and specialist palliative care team. Integrated palliative care criteria addressed by the intervention concerned holistic needs' assessment and palliative care interventions to reduce suffering, advance care planning and the involvement of a palliative care team. Care integration fostered better anticipation of events and patients' self-confidence, increased end-of-life discussions and allowed better symptom control compared to the control group. No difference was registered in terms of emergency department service utilisation.

The multidisciplinary intervention studied by Horton and colleagues in an observational longitudinal study consisted of a home-based palliative care consultation with a physician and nurse and involvement of the primary care team with the general practitioner.[49] Discussions about illness limitations and prognosis and continuous goal adjustment along the disease trajectory were held. Furthermore, holistic needs' assessment and symptom management were other integrated care criteria addressed by the study. Patients and caregivers reported an overall satisfaction with the intervention, nonetheless overall quality of life assessed through questionnaires remained unchanged. Furthermore, as reported by Aiken *et al*., a lack of impact on emergency department utilisation was observed.

Holistic needs' assessment and optimal symptom management are listed among criteria defining integrated care.[47] Integration of care in disease-modifying approaches may promote better symptom control. Higginson and colleagues describe in their randomized controlled trial the effectiveness of a breathless support service, integrating palliative care, respiratory medicine, physiotherapy and occupational therapy on symptom management. Patients in the intervention group reported a significant improvement of their breathlessness compared to controls.[40]

Lastly, economic evaluations of palliative care integration in services for patients with advanced COPD are very scarce.[50,51] In their observational retrospective study Cassel and colleagues described the effect of a home-based palliative care program for patients with COPD, cancer, chronic heart failure and dementia in the United States. A multidisciplinary team trained in palliative care and consisting of a nurse, a social worker, a spiritual care provider and a palliative care physician (mostly acting as a supervisor) visited patients at home at scheduled intervals. Discussions of illness limitations and prognosis and advance care planning defined integration of care. COPD patients reported an overall good experience with the proactive palliative care intervention. Hospitalisation and length of stay were significantly lower than in the control group, although non-hospital costs did not significantly differ between the two groups. Kirkpatrick and colleagues highlighted similar results in a small study about an in-patient integrated practice unit in the United States. A multidisciplinary team (respiratory and palliative care professionals, nurse practitioner, social workers and home health workers) provided care for patients with acute COPD exacerbations. Furthermore, follow-up appointments and post-discharge phone calls were planned. Holistic needs' assessment, symptom management and advance care planning reduced the 30-days readmission rate.[51]

## Discussion

This integrative literature review identified elements of what could become a developing taxonomy for palliative care delivery in advanced COPD services. These findings describe how palliative care is currently provided for patients with advanced COPD and how services work together. Consultation and referral are two different ways to provide palliative care. In consultation services, the leadership of care is maintained by the treating team and palliative care specialists are asked to render an opinion on a specific issue. Referral shifts the responsibility of care towards the palliative care team as a transfer of care. Collaboration is the expression of a more complex service delivery, where working closely together fosters the development of interdisciplinarity. The last step in this process is care integration, where a common organizational framework is created and continuity of care is the focus of care provision. This developing taxonomy and its different models of care delivery are illustrated in **Figure 2**.

The process is initialised by patients and informal caregivers' experiences and perceptions. Patients with advanced COPD present with a high symptom burden and an important need for ongoing communication with their healthcare professionals.[33] Exploring needs and views about advanced COPD and palliative care provision promotes the identification of unmet areas in current palliative care provision in this population and supports a developmental process of palliative care integration.[27,28] Open and honest communication between patients and healthcare professionals about disease prognosis and time limitation may foster palliative care acceptance while reducing misconceptions about palliative care being only recommended in end-of-life care.[28]

The timing of palliative care provision in advanced COPD remains unclear.[25] Worsening COPD is characterised by disease exacerbations that require hospitalisation, progressive decline of all functions, need for assistance with self-care and long-term oxygen treatment. The identification of these milestones in the disease trajectory may be used to promote an holistic assessment and should trigger the introduction of supportive interventions for this population based on pre-specified common criteria, while fostering the development of integrated care.[31]

Referral to a palliative care team entails a shift of care responsibility and a loss of continuity of care with healthcare professionals who followed patient and caregivers during their disease trajectory. An increased collaboration between all involved carers may help to approach the multidimensional needs through interdisciplinarity and enhanced professional expertise.[37] Finally, care integration may support an holistic assessment and management, and continuous discussions about illness limitations, prognosis and goals of care, while maintaining continuity of care for both patients and families in a common organizational framework for primary healthcare teams and palliative care specialists.

Palliative care service delivery in advanced COPD remains in a developmental phase. Different models of care provision with progressive levels of integration have been proposed.[38-40] Siouta and colleagues identified a framework for integrated palliative care in chronic disease. This framework promotes palliative care integration in the disease trajectory in concurrence of disease-modifying therapies. Furthermore, symptom control, consultations for patients and family members and training of healthcare professionals are provided by a trained multidisciplinary palliative care team. The moving force in this framework, as in the developing taxonomy of palliative care provision identified in this integrative literature review is the entirety of patients' and families' needs and their multidimensional approach.

Inadequate management of palliative care needs and care fragmentation are among the risks of models which do not provide integrated palliative care.[37] Integration of palliative care should consider the following four aspects: patients' and caregivers' needs, the awareness on palliative care provision in COPD, the importance of continuity of care and the need for an organizational change for care integration. Healthcare policy maker should be motivated to support novel care models and patients' organizations need to increase the awareness on the right of accessibility to palliative care for advanced COPD patients.[43,44] This motivation may be reinforced by outcome measures underlining the positive impact of palliative care provision in advanced COPD. Therefore, further evidence on the benefit of palliative care service delivery is needed to support the developmental process of care integration in advanced COPD.[50] Cost-effectiveness of palliative care integration in advanced COPD and economic outcomes should be included in future investigations about this type of service delivery, in order to support the development of new care models.[49]

There are several strengths in this systematic review. To our knowledge, this is the first systematic review which synthesizes empirical evidence on how palliative care is provided for people with advanced COPD. Furthermore, papers with various methodological backgrounds have been included in the review, thus enriching data synthesis and strengthening the results. Nonetheless, some limitations need to be addressed. The use of a sole critical appraisal tool for disparate data may increase the risk for quality rigour. Therefore, the threshold for quality assessment was set in the higher scores of the chosen appraisal checklist.

In conclusion, this integrative literature review identified elements of a developing taxonomy of palliative care delivery in advanced COPD. Further research is needed to define timing of palliative care integration and referral criteria for advanced COPD. Moreover, it is pivotal to explore the extent and quality of palliative care services provided by primary care teams and what kind of leadership they could assume working in an integrated care team.

## Declaration of interest

No conflict of interest is to report by the authors.

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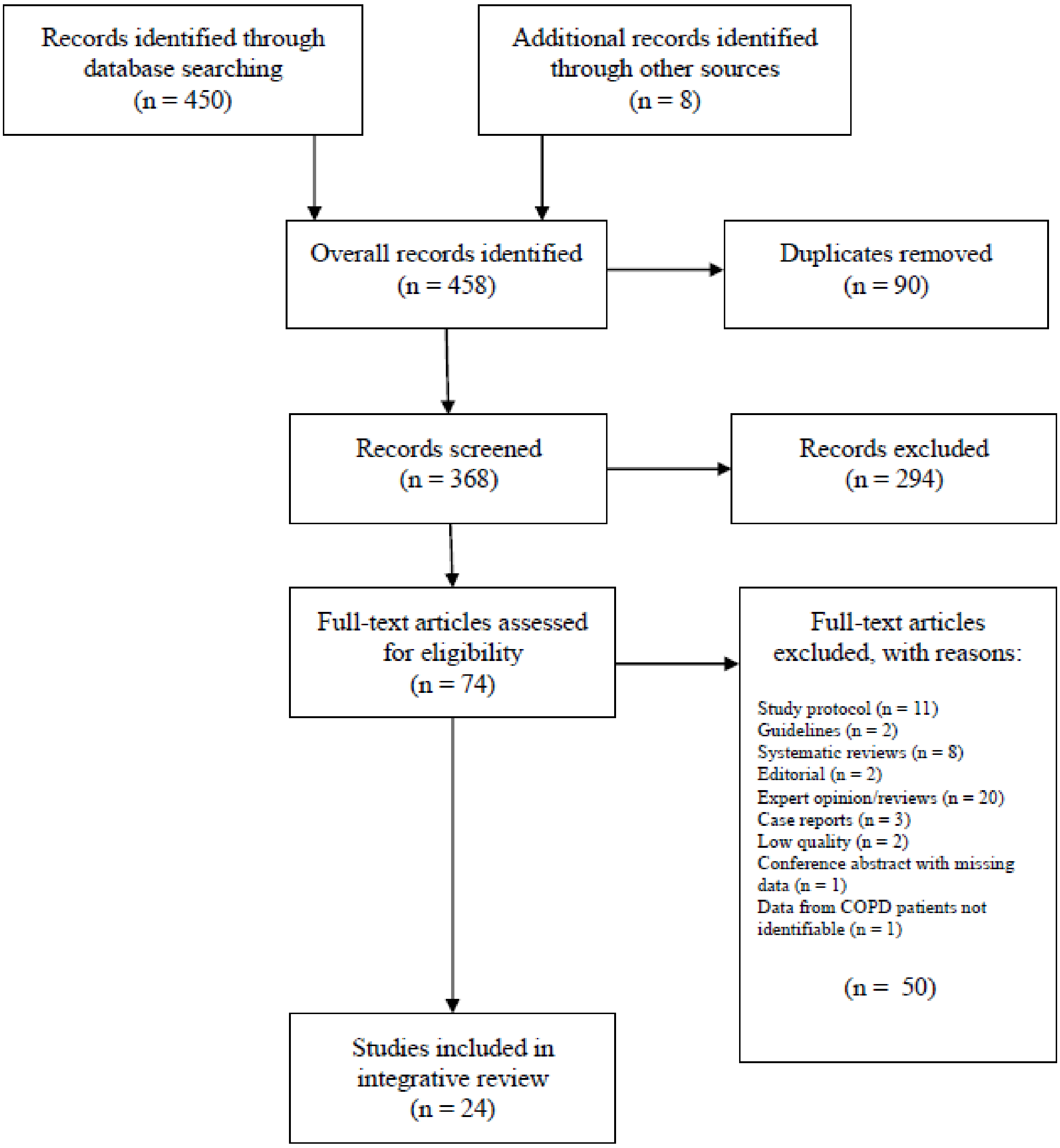

**Figure 1**: Flow diagram for study inclusion

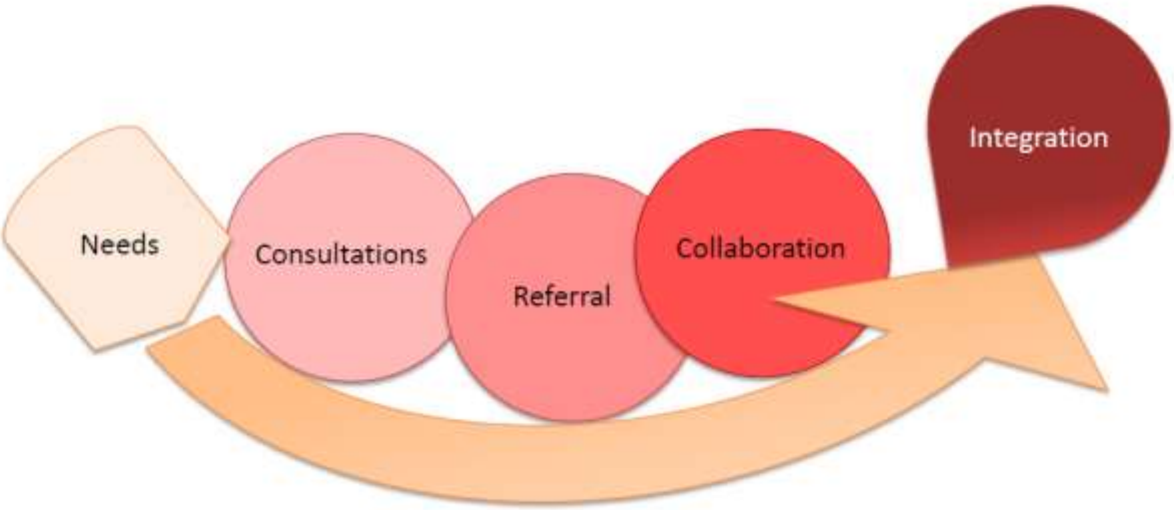

**Figure 2**: Developing taxonomy for palliative care provision in advanced COPD

**Table 1**: Inclusion and exclusion criteria for studies

| **Inclusion criteria** | **Exclusion criteria** |
|---|---|
| **Population**: *Adults (defined as over 18 years old) living with end-stage COPD*<br>Studies were included either when they considered COPD patients alone or in combination with other life-limiting illnesses (e.g. cancer) | Papers describing non-empirical research<br>Full text not available (for any reason)<br>Papers with unclear results distinction for the COPD population |
| **Phenomena of interest**: *Development of palliative care integration* | |
| **Context**: *any health service (inpatient, outpatient, homecare) worldwide*<br>Language restriction to studies reported in English, French, German, Italian and Spanish | |
| **Study design**: *any study design (qualitative, quantitative, mixed methods)* | |

**Table 2**: Characteristics of studies included in the integrative review

| Authors<br>Year<br>Country | Context | Palliative care definition | Aims | Study design | Sample | Quality assessment |
|---|---|---|---|---|---|---|
| **Aiken et al.**<br>2006<br>USA | Home care | Multidisciplinary team<br>Advance care planning<br>Symptom relief<br>EOL discussions | To document outcomes on self-management, preparation for EOL, physical and mental functioning and ED visits of a coordinated PC program | Randomized controlled trial | 100 patients (33 with COPD) in intervention group, 90 controls (28 with COPD) | 33 |
| **Beernaert et al.**<br>2013<br>Belgium | Outpatients in GP practices | Not mentioned | To describe how patients with different life-limiting illnesses differ in terms of frequency and timing of referral to PC | Retrospective, population-based study | 2405 registered deaths of which 111 from COPD | 35 |
| **Buckingham et al.**<br>2015<br>UK | Home care | Not mentioned | To identify and address holistic care needs of people with severe COPD through a novel nurse-led intervention | Mixed-methods feasibility pilot trial | 32 patients with COPD | 33 |
| **Burgess et al.**<br>2013<br>Australia | Public/private primary and specialist care | Not mentioned | 1) To explore service availability and accessibility for people with advanced COPD and their carers and<br>2) To assess the role of a care-coordinator | Qualitative study through focus groups and interviews | 8 GP, 6 respiratory nurses, 8 PC nurses and social workers, 4 respiratory physicians, 8 community care nurses, 30 people from COPD community support group, 20 people from hospital respiratory team, 2 representatives from carer support group and 2 community service provider | 34 |
| **Buxton et al.**<br>2010<br>UK | Hospital | Not mentioned | To assess current and planned PC service delivery for COPD in comparison with GSF | Web-based survey (national audit) | 239 respiratory units in UK | 31 |
| **Cassel et al.**<br>2016<br>USA | Community setting | Multidisciplinary team | To evaluate the nonclinical outcomes of a proactive palliative care program | Observational, retrospective study using propensity-based matching | 370 patients (66 with COPD) in intervention group, 1075 controls (111 with COPD) | 32 |
| **Cawley et al.**<br>2014<br>UK | Primary/secondary care | Not mentioned | To identify events which potentially could act as triggers for PC provision | Qualitative in-depth interview | 21 patients, 13 informal caregivers, 18 professionals | 36 |

| Authors<br>Year<br>Country | Context | Palliative care definition | Aims | Study design | Sample | |
|---|---|---|---|---|---|---|
| **Crawford et al.**<br>2012<br>Australia | Urban hospital and rural clinic | Not mentioned | 1) To explore the needs of people with end-stage COPD in South Australia and<br>2) To develop recommendations for a model of care | Qualitative multi-perspective approach (interviews, focus groups, group sessions and expert panel | 15 patients and 8 caregivers for interviews; 13 HCP for expert panel; 34 HCP for focus group and 20 people from consumer support for group session | 35 |
| **Duenk et al.**<br>2017<br>Netherlands | Hospital | WHO definition | To explore the view of respiratory care physicians on PC in general, for COPD patients and on organization of PC for COPD | National study survey | 256 respiratory care physicians covering 85.9% of the hospital organizations in the Netherlands | 35 |
| **Elkington et al.**<br>2004<br>UK | All care settings | | 1) To assess symptoms experienced and their impact on patient's lives in the last year of life of COPD and<br>2) To assess access to healthcare services | Qualitative in-depths interviews | 25 carers of COPD patients who had died in the preceding 3-9 months | |
| **Epiphaniou et al.**<br>2014<br>UK | Teaching hospital and home care | Optimize quality of life<br>Provide holistic care | To explore patients' experience of care coordination in patients with life-threatening diseases such as lung cancer and COPD | Longitudinal qualitative interview study | 18 patients (7 with COPD); total of 38 interviews (14 with COPD patients) | 34 |
| **Goodridge et al.**<br>2009<br>Canada | All care settings | Initiating dialogue and EOL planning<br>Anticipating the need for EOL<br>Advanced care planning<br>Optimizing interdisciplinary team care<br>Selecting interventions for patients with COPD | To discuss the applicability, development and monitoring of indicators measuring the quality of end-of-life care for individuals with advanced COPD | Consensus meeting (Delphi process) | 15 HCP, patients and informal caregivers (not defined) | 31 |
| **Hayle et al.**<br>2013<br>UK | In- and outpatients | Not mentioned | To evaluate the experiences of patients with COPD who accessed specialized PC | Semi-structured interviews through hermeneutic phenomenological approach | 8 patients with COPD | 36 |
| **Higginson et al.**<br>2014<br>UK | Outpatients | Symptom control<br>Multidimensionality<br>Interdisciplinary team | To assess effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness | Randomized controlled trial | 53 patients (29 with COPD) in intervention group, 52 patients (28 with COPD) in standard care | 36 |

| **Authors**<br>**Year**<br>**Country** | **Context** | **Palliative care definition** | **Aims** | **Study design** | **Sample** | |
|---|---|---|---|---|---|---|
| **Horton et al.**<br>2013<br>Canada | Home care | Assessment of symptoms<br>Understanding of illness<br>Goals of care<br>Multidimensional treatment<br>Individualized treatment plan | 1) To determine the feasibility of implementing a customized home-based palliative care service for patients and caregivers living with advanced COPD and<br>2) To measure outcomes of such services | Single-centre cohort longitudinal observational study | 30 patients with COPD and 18 caregivers | 32 |
| **Hynes et al.**<br>2015<br>Ireland | Hospital (both urban and rural services) | WHO definition<br>Improve quality of life<br>Multidimensionality<br>More than EOL | To explore the conflict between acute care and PC, bringing into question the feasibility of embedding PC principles in acute care environment in COPD | Two-phased action research project | Phase I: interview with 26 patients<br>Phase II: co-operative inquiry group (6 nurses from respiratory and PC team) | 35 |
| **Kirkpatrick et al.**<br>2014<br>USA | Hospital/home-based | Not mentioned | To evaluate reduction of 30-days readmission rate for AECOPD with Integrated Practice Unit | Pre-/post-intervention observational study | 110 patients pre-intervention, 114 patients post-intervention | Not available (conference abstract) |
| **Landers et al.**<br>2015<br>New Zealand | Home care | Focus on quality of life | To explore the experience of patients with advanced COPD after a life-threatening event, with a focus on EOL issues | Grounded theory guided interviews | 15 patients with severe COPD | 35 |
| **Partridge et al.**<br>2009<br>UK | Hospital | Not mentioned | 1) To elucidate availability and access to specialist palliative care services,<br>2) To identify availability of NIV within specialist PC services,<br>3) To determine the existence or otherwise of formal policies for EOL in chronic lung diseases and<br>4) To seek respiratory physicians view on specialised PC services for their patients | Survey | 107 respiratory care physicians | 30 |
| **Pinnock et al.**<br>2011<br>UK | Primary and secondary care | Not mentioned | To understand the perspectives of people with severe COPD, their informal caregivers and professionals | Longitudinal qualitative study | 21 patients, 13 informal caregivers, 18 professionals | 36 |
| **Rocker et al.**<br>2014<br>Canada | Home care | Not mentioned | To evaluate the effect of a supportive program of individualized care for patients and families on ED visits, hospital admissions and hospital stays | Pre-/post-intervention observational study | 93 patients pre-intervention and post-intervention | 30 |

| **Authors**<br>**Year**<br>**Country** | **Context** | **Palliative care definition** | **Aims** | **Study design** | **Sample** | |
|---|---|---|---|---|---|---|
| **Schroedl et al.**<br>2014<br>USA | Outpatients in PC clinic | Not mentioned | To describe an outpatient PC program for patients with COPD | Retrospective case series | 36 patients with COPD | 31 |
| **Spence et al.**<br>2009<br>UK | Acute and community care settings | Not mentioned | To determine whether professionals felt patients had PC needs and explore barriers faced by HCP in delivering PC to patients with COPD | Qualitative approach through interviews and focus groups | 23 health and social care professional0073 | 33 |
| **Strang et al.**<br>2013<br>Sweden | All care settings | WHO definition | To explore the perceptions of respiratory physicians in relationship to medical and organizational aspects of PC in COPD | Web-survey | 93 respiratory care physicians | 31 |

ED = emergency department, EOL = end-of-life, GP = general practitioner, GSF = gold standard framework, HCP = healthcare professionals, NIV = noninvasive ventilation, PC = palliative care

**Table 3**: Identified themes and sub-themes

| Main themes | Sub-themes | | |
|---|---|---|---|
| **Experiences and perceptions about living with advanced COPD and palliative care provision** | **High symptom burden and holistic assessment of needs** | **COPD as a "way of life"** | **Need for enhanced communication (advance care planning, end-of-life care)** |
| | Multidimensional needs, often underreported **(**Elkington *et al*., Cawley *et al*., Schroedl *et al*.) | Living with COPD becomes "normal", adjusting to progressive worsening of symptoms over months and years (Landers *et al*., Pinnock *et al*.) | Patients' awareness of their disease trajectory a discussions about advance care planning reduce misconceptions about palliative care provision (Hayle *et al*., Schroedl *et al*., Spence *et al*.) |
| **Palliative care timing** | **Milestone of decline** | **Specific palliative care criteria** | |
| | Events which define disease progression and should promote PC provision (Cawley *et al*., Landers *et al*., Pinnock *et al*.) | Consensus on criteria which identify palliative care patients (Duenk *et al*., Partridge *et al*.) | |
| **Service delivery** | **The "Solo Practice Model"** | **The "Congress Practice Model"** | |
| | Skilled primary care teams can deliver high-quality palliative care (Beernaert K *et al*., Buxton *et al*.) | Specialist consultations as needed (Buckingham *et al*., Goodridge *et al*.) | |
| **Models of care integration in advanced COPD** | **Development of integrated care** | **Integrated palliative care models** | |
| | *Reduction in care fragmentation*<br>Integration of care may foster coordinated care with patient-centered models (Goodridge *et al*., Crawford *et al*.)<br><br>*Shift in care organization*<br>Need to raise awareness in healthcare organizations (Beernaert *al*., Hayle *et al*., Hynes *et al*., Strang *et al*.)<br><br>*Care-coordinator*<br>Model for a care-coordinator to support patient-centered care (Burgess *et al*., Elkington *et al*., Epiphaniou *et al*.) | Different models for palliative care integration (Aiken *et al*., Cassel *et al*., Higginson *et al*., Horton *et al*., Kirkpatrick *et al*.) | |

**Table 4**: Included studies with integrated care criteria

| **Authors**<br>**Year**<br>**Country** | **Integrated care interventions** | **Integrated palliative care criteria (Emanuel *et al*., 2004)** | **Outcomes for integrated care** |
|---|---|---|---|
| **Aiken et al.**<br>2006<br>USA | Home-based palliative care (PC) intervention services<br>Registered nurse case managers provided service and coordinated care with PC team and GP<br>Support by social worker and pastoral counselor<br>Scheduled visits for the team, on call visits if needed | Advance care planning<br>Holistic needs ‘assessment<br>PC interventions to reduce suffering (physical and psychological symptom control)<br>PC team involvement | Increased self-management of illness and knowledge of resources<br>Higher percentages of advanced care planning<br>Better symptom control<br>No difference between intervention and control group in emergency department visits |
| **Cassel et al.**<br>2016<br>USA | Home visits by multidisciplinary team (nurse, social worker, spiritual care provider and PC physician), added to disease-focused care<br>All staff trained in general PC, PC physician acts as supervisor | Discussions of illness limitations and prognosis<br>Advance care planning<br>PC team involvement | Reduced hospital costs, reduced overall hospitalizations and in the last month of life<br>No impact on overall costs (non-hospital) |
| **Higginson et al.**<br>2014<br>UK | Breathlessness Support Service: multiprofessional service (respiratoy, physiotherapy, occupational therapy and PC assessment)<br>Outpatient visit: PC and respiratory care clinicians<br>Home visit: physiotherapist and/or occupational therapist | Holistic needs ‘assessment<br>PC interventions to reduce suffering (physical and psychological symptom control)<br>PC team involvement | Improving breathlessness mastery in intervention group<br>Improved survival rate in intervention group |
| **Horton et al.**<br>2013<br>Canada | Home-based PC interventions<br>PC physician and nurse consultations at home<br>Discussions with GP and primary care team<br>Scheduled visits for the team, on call visits if needed | Discussions of illness limitations and prognosis<br>Holistic needs ‘assessment<br>PC interventions to reduce suffering (physical and psychological symptom control)<br>PC team involvement<br>Continuous goal adjustment as the illness and the person’s disease progresses | Home-based PC interventions are feasible<br>Lack of impact on managing terminal symptoms (patients were hospitalised for terminal care despite home consultations) |
| **Kirkpatrick et al.**<br>2014<br>USA | Inpatient multidisciplinary team (respiratory and palliative care professionals, nurse practitioner, social workers, pulmonary rehabilitation, home health workers)<br>Follow-up appointments and post-discharge phone calls | Advance care planning<br>Holistic needs ‘assessment<br>PC interventions to reduce suffering (physical and psychological symptom control)<br>PC team involvement | Reduced risk for 30-days readmission |