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Review Paper

Title: Palliative and end of life care for adults with advanced chronic obstructive pulmonary disease (COPD): a rapid review focusing on patient and family caregiver perspectives

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Purpose of review

The aim of the review was to explore patient and family caregiver perspectives on key issues for ensuring quality of end of life care for people with chronic obstructive pulmonary disease (COPD). The growing evidence on the value of specialist palliative care services demonstrates significant improvements in treatments and provisions, however, much of the literature is generic in nature or centred on people with a cancer diagnosis. In this review we examine the literature to ascertain the views and needs of patients and carers affected by advanced COPD, a highly debilitating condition that can have a profoundly negative impact on the quality of end of life experience.

Recent findings: 19 papers were included in the review. The main themes in the literature were Holistic Care; Illness Trajectory; and Technology.

Summary Areas of unmet need emphasised across physical, psychosocial and spiritual domains were identified, in particular in relation to appropriate and timely conversations. Positive developments in the care and treatment of advanced COPD include the use of the STIOLTO Respimat inhaler, a brief educative and psychosocial intervention based on cognitive-behavioural therapy, and high intensity exercise training.

There is some evidence regarding the use of technology in end stage COPD. (198 words)

Keywords: rapid review, advanced chronic obstructive pulmonary disease (COPD), end of life care, palliative care, patient and carer preferences

Introduction

The World Health Organisation defines palliative care as, “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”¹. Palliative and end of life care globally is now considered a human right² and quality of life, care and death of people at the end of life is a growing public priority³⁻⁵. Yet, there are major gaps in the evidence regarding preference of death and factors influencing these in the area of non-malignant life limiting conditions⁶.

Chronic obstructive pulmonary disease (COPD) is a debilitating, progressive condition that is the fourth leading cause of death worldwide, claiming 3.2 million lives in 2015⁷. COPD is linked to multiple morbidity and symptoms such as cough, phlegm, breathlessness, discomfort, fatigue and acute exacerbations of the disease which can intensify respiratory symptoms⁸. It is diagnosed through spirometry. The presence of a post-bronchodilator FEV1/FVC of < 0.70 confirms the presence of persistent airflow limitation⁹. The disease, however, frequently remains undiagnosed until people have reached the moderate or severe stages of the disease trajectory by which time their quality of life is usually impeded¹⁰.

Although, in recent years, there have been noteworthy advances in the treatment for people living with chronic respiratory disease, curative treatment for advanced COPD is unlikely and life expectancy remains poor¹⁰. The extreme breathlessness associated with COPD can lead to rapid and major decline in physical capacity and affect the psychological integrity of patients¹¹. Other factors that may intensify the experience of living with this illness are economic issues and the presence of financial hardship¹². Family carers are often central support providers, helping people live with and manage the condition but challenges and responsibilities around treatment and care decision-making can bring additional stressors on top of dealing with everyday life. Despite an expressed desire of patients and family/informal carers to engage in discussions around end of life care, there is little evidence to suggest that the occurrence of such dialogue is commonplace within the context of COPD^{13, 14}. Moreover, people with advanced COPD worldwide often have difficulty accessing specialist palliative care services due to the variable trajectory and episodic breathlessness¹⁵.

The aim of the review was to scope information available from recently published empirical research to explore patient and family caregiver perspectives on key issues for ensuring quality of end of life care for people with chronic obstructive pulmonary disease (COPD).

We were primarily concerned with advanced/severe COPD and in people with a prognosis of one year or less, where that was possible to determine.

Methods of review

A rapid review of the literature was undertaken to explore key issues pertaining to quality in end of life care for people with COPD. A protocol was developed and agreed prior to starting the review which followed similar processes to that of a full systematic review but limiting the scope of the search by reducing the number of databases searched, excluding grey literature searching and placing limitations on search terms and eligible dates (see Appendix I). The search strategy was designed using a keyword search of articles related to the theme to identify terms used by previous authors in the field.

We included subjective and objective outcome measures but in studies where survey instruments were employed we considered only those which used published validated measures. The primary outcome measure was key issues pertaining to quality of palliative and end of life care identified by people living with COPD and their families. We were interested to identify empirical research articles on the basis of population, intervention, outcomes, and study design (Box 1), a modified version of the PICOS (Population, Intervention, Comparator, Outcome, Study design approach¹⁶.

We included only peer-reviewed research articles which reported on original research regardless of study type or country of origin but in the English language and published during the years (2015 -2017). Medical Subject Headings and free terms (see appendix I) were used to identify studies using the following databases: MEDLINE, EMBASE, CINAHL, CENTRAL and the University of Glasgow on-line Library. Articles meeting the inclusion criteria were downloaded into End Note and the full text of the articles obtained.

Quality appraisal

Both authors appraised all full text articles using the relevant Critical Appraisal Skills Programme (CASP) questions¹⁷⁻²⁰ to assess the quality of each study design. A scoring system was used that allowed the 10 CASP criteria to be scored: 0 meaning criterion not fully addressed, 1 partially addressed and 2 the criterion was fully addressed. A total score between 15-20 or 20-26 when total 26 was considered high quality, whereas a score of 0-7 was low quality. Findings were recorded using a flowchart as with recommended practice²¹ (Fig. 1). Differences were resolved through consensus discussion and the results were tabulated (See Table 1).

A total of 19 papers were included in the final review. The 19 included studies were conducted in 13 countries: Australia (n=2)^{22, 23}; Canada, Denmark and Norway (n=1)²⁴; Denmark (n=1)²⁵; Germany (n=1)²⁶; Greece (n=1)²⁷; Italy (n=1)²⁸; the Netherlands (n=1)²⁹; New Zealand (n=1)³⁰; Spain (n=2)^{31, 32}; Sweden (n=1)³³; United Kingdom (UK) (n=3)³⁴⁻³⁶; United States of America (USA) (n=3)³⁷⁻³⁹; USA and Germany⁴⁰. The study designs comprised: randomised controlled trials (RCT) (n=3)^{22, 25, 34}; systematic and literature reviews (n=3)^{24, 28, 31}; qualitative research studies (n=9)^{26, 27, 30, 32, 33, 35-37, 41}; other studies - secondary analyses (n=3)^{29, 40, 42}; retrospective observational studies (n=1)³⁹.

Data were analysed descriptively and the themes identified as most important in relation to the study aim are reported here: 1) Holistic Care; 2) Illness Trajectory; 3) Technology.

Holistic Care - *Physical*

The importance of adopting a holistic approach to COPD caring was highlighted in the range of topics uncovered. These crossed several domains including physical, psychosocial and spiritual needs. Control of physical symptoms of COPD through optimising medicine use comprised the central focus of two studies ^{40, 42}. Both studies analysed pooled data from earlier drug trials. Ferguson et al. (2017) sought to establish the efficacy of STIOLTO Respimat, a combination of two bronchodilators-tiotropium, and olodaterol, to address airway obstruction and breathlessness and improve long-term lung function. Outcomes showed that the new drug combination brought significant improvements in patients' quality of life, breathlessness and also reduced the use of night-time rescue medication. Ferreira et al. (2016) found that, in participants with chronic refractory breathlessness, and particularly in younger populations, there was a marked preference for morphine over placebo³⁸. Inverse relationships were, however, found between morphine preference and sedation and between nausea and morphine preference. These results emphasise the clinical potential of morphine for symptom control in COPD but also demonstrate the need for a rigorous approach to combat negative side effects.

A systematic review and meta-analysis evaluating the effectiveness of exercise training in patients with very severe COPD demonstrated functional improvements and enhanced health-related quality of life following exercise training ²⁸. Prescriptions for supervised high intensity cycling or walking training with incremental testing to achieve optimum velocity are advocated as an important strategy to promote positive clinical change in this group of people.

Qualitative explorations on patient experiences and preferences of non-invasive ventilation (NIV) in chronic obstructive pulmonary disease in domiciliary³⁵ and tertiary settings⁴¹ illuminated the lack of convergence between health professional and patient perspectives on the purpose of, and need for, NIV. It emerged that patients felt under pressure to accept the recommendations of health professionals to use NIV and that adaptation to continuing use, given the drawbacks of this treatment, was strongly influenced by the knowledge base, support levels of the health professionals involved, and perceived concordance with their views³⁵.

Holistic Care - *Psychosocial*

A randomised controlled trial comparing a minimal home based, nurse-led, psycho-educative intervention based on comparing Cognitive Behavioural Therapy (CBT) to usual care proved acceptable to patients with COPD²⁵. This was demonstrated through high compliance and sustained benefits over time shown through clinically significant changes in the Hospital Anxiety and Depression –subscale anxiety scores (HADS-A)⁴³ post intervention compared with the control group. Findings were reinforced by the qualitative interview data but the transferability of the St. George Respiratory Questionnaire (SGRQ) to this Danish population was, however, uncertain due to the general lack of patient completion.

A systematic review on relationships between COPD symptoms and disease burden across different life domains highlighted the need for improved recognition and understanding of the impact of COPD symptoms and burden³¹. Long-term treatment plans incorporating

routine assessment of symptoms using patient-centred methods were advised to ensure effective 24 hour management. In similar vein, a secondary analysis of a longitudinal observational study on caregiver burden and the positive aspects of caregiving exposed the changeable and highly individual nature of caregiver burden²⁹. The need for healthcare professionals to pay regular attention to the particular needs of family caregivers, regardless of the patients' characteristics, was raised as a key facet of family-based care.

The importance of undertaking key conversations to establish the personal preferences of patients and to provide relevant and timely information on COPD was a recurrent theme. Studies referring to Advance Care Planning (ACP) revealed that patients commonly evade discussing their prognosis and difficult topics relating to COPD²³. The challenges of such conversations were evident both between patients and family members and between both patients and family members and health professionals. The findings demonstrated that, although, the majority of people with COPD prefer to not undergo cardiopulmonary resuscitation (CPR), in the main, the issue is not discussed with health professionals⁴¹. A recent retrospective review of medical records following a successful trial intervention to increase the incidence of end-of-life conversations showed that the primary outcome was not associated with a higher percentage of patients with documented unique end-of-life care conversations or completion of advance care directives compared to the control group³⁹.

Holistic Care - *Spiritual*

A qualitative interview study was undertaken to understand Greek COPD patients' perceptions of spirituality and religiosity and to explore the importance of practising their belief²⁷. The authors described a lack of attention to religious and spiritual needs in the context of clinical care, despite the fact that the majority of participants (84%) expressed religious and/or spiritual beliefs. Faith in the will of God and the importance of praying and church attendance featured strongly as a supportive factor in patient coping with COPD but functional limitations of the illness created a barrier to regular churchgoing, raising important issues about unmet need in this area.

Illness Trajectory - *Uncertainty and loss/ Timing of interventions*

Key patterns in the illness trajectory of advancing COPD were identified by several authors^{26, 30, 32-34}. These emphasise the unpredictable nature of COPD illness progression accompanied by resultant uncertainty and feelings of disempowerment experienced by patients and carers. Although acute episodes are often succeeded by an improvement in the condition and ongoing survival the intense nature of these exacerbations often intensifies the fear of death³³. Interestingly, panic attacks, not breathlessness have been purported as markers of advanced disease although the feeling nature of adverse psychological experiences are often not openly shared by patients^{30, 32}. Reduction in mobility and social exclusion exert increasing influence on core illness experience with patients and carers describing feelings of being at the mercy of the illness whilst striving to maintain some semblance of normality²⁶. The roller coaster experience of the COPD illness trajectory can lead to emotional exhaustion and continual worry about the future. Recent evidence strongly points to the need for better case management to help families prepare

for uncertainty and to more effectively address the physical, psychosocial and spiritual needs of patients^{26, 30, 32-34}. Transition points and specific triggers such as hospital admission have been spotlighted as potentially useful entry points for conducting holistic needs assessment^{32, 34, 41}.

Findings also, however, emphasise challenging issues relating to acceptance of professional support. It appears that, from the patient perspective, current treatments (including rescue medication) can provide effective symptom management over a sustained period until the point of physical incapacity is reached²⁶. The efficacy of acute care interventions and treatment regimes in the earlier and intermediate stages of COPD bring security³⁰. Paradoxically, this can foster misunderstandings about future prognosis that can impair coping with end stage experience when physical deterioration is associated with a marked drop in mental and social wellbeing²⁶.

Recent qualitative research identified the inadequacy of information given to patients and carers resulting in uncertain knowledge and the formulation of interpretations about COPD that tend to either minimise its severity or exacerbate worry^{26, 32, 44}. The need for positive communication including lay explanations on definitions, cause, process and incurability of COPD is recommended to help improve patient understanding of the illness^{26, 32, 35}.

Providing health promotion that does not promote assignation of responsibility (smoking cessation advice often promotes feelings of responsibility yet patients are reluctant to accept this) requires sensitivity and skill^{26, 32}. The advance of COPD is unremitting and

lifestyle changes often occur too late to make a difference to life quality, highlighting, the need for timely intervention.

Technology

Stakeholder perspectives on developing a Web-based advance care planning tool for lung disease showed that this was a potentially useful and acceptable means of care provision³⁷. Patients suggested that the use of videos of medical scenarios and patient narratives would be preferable to textual information. Patients liked the concept of interactive content that was under their own control so they could decide how much to complete in a single sitting. Participants also identified challenges and potential solutions, such as how to manage the emotional difficulty of thinking about death and accommodate low computer literacy users.

The usefulness of the Health Information Technology Acceptance Model (HITAM) for understanding acceptance of Health Information Technology (HIT) was examined in a RCT for older people with COPD and associated heart diseases (CHROMED)³⁶. Results showed that self-management of HIT was linked to a good organisational framework, ergonomics and informal, accessible support. Drawbacks were associated with patient concerns about less face-to-face health professional contact and heightened illness anxiety through the more frequent monitoring of health status. The perceived usefulness of HIT was related to establishing trends in health status, detecting early signs of infection and potential to self-manage, all health professional driven outcomes.

A recent pilot trial examined the effects of home tele-monitoring (TM) of patients with severe chronic obstructive pulmonary disease (COPD) ²². TM appeared to delay the

incidence of COPD-related exacerbations requiring a hospital visit and to reduce the level of COPD-related emergency presentations at hospitals, subsequent admissions to hospital and the length of in-patient stays. Collectively, these improvements were noted to have a beneficial impact on the costs of hospital care. TM was perceived to be accepted by most patients and nursing staff but positive impacts were confined to physical well-being outcomes. Caution needs to be applied to conclusions from this study due to the small sample size and high attrition. The

Discussion

This review has highlighted recent positive developments in the care and treatment for people living with advanced COPD. Advances in drug treatment, exercise therapy and psychological interventions have been shown to promote well-being and quality of life. The role of technology also shows promise but the benefits of this require further investigation to ascertain how this can best be utilised to emphasise patient rather than professional benefit.

An important sub-theme of this review was the lack of congruence in some relationships between health care professional and patients/carers signalling the need for more in-depth and timely conversations about the nature of COPD, its progression, prognosis and treatment options. Authors here have highlighted a reluctance on the part of health professionals to engage in discussions about sensitive issues and the need for improved education and training to inform and facilitate these^{23, 26, 30, 35, 44}. Where work has been undertaken to remedy these factors, insufficient documentation may have resulted in a failure for patient wishes to be upheld, negating the potential of initial benefits³⁹.

Furthermore, it has been indicated that, there is a need to assess the quality of existing care

prior to the introduction of new interventions to prevent duplication and promote harmonisation of care^{22, 34}.

The fluctuating and unpredictable nature of chronic respiratory illness suggests the benefits of ongoing holistic assessment commenced at an earlier stage in the disease trajectory. The evidence here indicates, however, that people do not often not desire of professional input and wish to maintain personal autonomy over their illness management even when significant symptom burden is present^{26, 30, 34}. The issue of perceived patient resistance to early professional intervention requires further investigation to establish whether it is the nature of professional inputs that are the problem rather than a patient reluctance to explore difficult issues. The research reported here exemplifies that models of care need to be closely informed by patients and focus on maintaining normality for as long as possible. Dealing with a terminal illness can elicit feelings of vulnerability and lack of autonomy⁴⁵ with the failure to express unmet care needs a key issue for attention in respect of end of life care⁴⁶⁻⁴⁹. Optimal palliative and end of life care interventions facilitate patient preferences on care practices and choice of place of death^{4, 5, 50} but the need for expert knowledge and understanding of particular disease processes and treatments is a key facet in supporting patient acceptability choice.

The increased use of home-based brief interventions that encompass holistic assessment may indicate a useful opportunity for developing closer relationships with patients and carers. These can provide continuity of care through monitoring patient and carer status throughout the different disease milestones whilst offering judicious and discreet psycho-social support. This approach may also help to open channels of communication for deeper

conversations about end of life and related issues and points to the role of trained community workers, especially nurse specialists.

Limitations

Due to time restrictions we did not search all relevant databases or search the grey literature. In carrying out a modified search we may have failed to identify additional articles and other material such as unpublished conference abstracts, policy documents, and technical reports. Neither did we search for study protocols of RCTs in process or contact any of the primary authors. Our focus was specifically on the care needs of people living with advanced COPD and their families thus we excluded a number of studies that are of relevance to earlier stages of this condition. The descriptive analysis offers an overview of the current literature rather than the increased critical precision provided by a full systematic review with meta-analyses or meta-syntheses. Finally, findings represent a global spread of nations but these are all developed countries with advanced health systems thus, although greater homogeneity may be indicated, insights are restricted to these domains.

Conclusion:

Illness trajectories highlight the changing pattern of COPD illness progression and emphasise a range of unmet needs. Early interventions of palliative care are proposed by policy makers and supported by health professionals but getting the timing and the ingredients right is a key factor. Care interventions need to be based on patient preferences rather than professionally driven. Positive findings in respect of the STIOLTO Respimat inhaler are encouraging. Psychosocial interventions exercise, and the prudent use of technology also

convey promise but the limited research in people with advanced disease calls for further studies to confirm the value of these approaches.

Key points:

- Despite positive intentions a lack of converging attitudes between health care professional perspectives and patients/carers means that the concept of holistic care remains an ideal rather than a reality with areas of unmet need emphasised across physical, psycho-social and spiritual domains.
- Positive developments in the care and treatment of advanced COPD include the use of the STIOLTO Respimat inhaler, a brief educative and psychosocial intervention based on cognitive-behavioural therapy, and high intensity exercise training.
- There is mixed evidence of patient benefit, especially in respect of improved autonomy, from the use of technology in end stage COPD but this approach can be maximised through patient and carer involvement in the design, development and delivery of interventions.

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3. Conflicts of interest

For the remaining authors none were declared.

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- Patients with COPD and their relatives in this study lived with uncertainty up until the time of death. Little support for psychosocial and existential needs was available. Un met need in this area needs to be addressed. It is essential for the nurse to create relationships with patients and relatives that enable them to talk about dying and death on their own terms.*
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The aim of the journal is to provide the readers with a guide to the best literature published this year. Please mark some of the references you have used (published in the last two years only) as of special (*) or outstanding (**) interest and give a short annotation to each of these describing the paper's importance.

Box, figure and table legends

Box 1 Inclusion criteria

Fig.1 Flow chart of included studies

Table 1. Articles included in the review