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Palliative and Supportive Care in Chronic Obstructive Pulmonary Disease: Research Priorities to Decrease Suffering

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Abstract

Chronic obstructive pulmonary disease (COPD) affects 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability. Despite the similarities with malignant disease, many individuals suffer unnecessarily and continue to have limited access to palliative and end-of-life care. Changing this will require a shift in focus and approach as well as support for clinical decision making. Lack of communication regarding care plans and prognosis and coordination across care settings has been identified as barriers to end-of-life care. Research specifically should focus on improving the use of comprehensive and collaborative approaches to end-stage COPD care such as those illustrated in the Chronic Care Model which has demonstrated improved outcomes for chronic conditions. Revision of funding models and workforce organisation, aided by clinical pathways may improve end of life care for COPD.

Keywords: Chronic obstructive pulmonary disease (COPD); Palliative care; Research priorities

Abbreviations: COPD: Chronic obstructive pulmonary disease; WHO: World Health Organisation

Introduction

Chronic obstructive pulmonary disease (COPD) affects 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability [1]. Despite the high symptom burden and parallels with malignant disease, individuals with end-stage COPD continue to have limited access to palliative and end-of-life care and suffer unnecessarily [2-4]. Social isolation, difficulties in prognostication and a focus on the acute crisis, create care that is reactive, burdensome to informal caregivers and ad hoc rather than a collaborative approached shared across acute life sustaining care and palliative services [3-7].

The increasing prevalence of COPD [1] challenges the provision of effective health care interventions, particularly in the context of an aging population who commonly present with multiple chronic conditions [1]. This is aggravated by the contentious and value laden dimension of end-of-life care. Key research priorities for palliative and supportive care were identified through the issues raised in the following data sources:

1. International policy and strategy documents [8-10];
2. Evidence for palliative care interventions for COPD [11-13];
3. Discussion documents and opinions pieces regarding the need for improvements to COPD care [8,14]; and
4. Two previous reviews undertaken by the research team [15,16].

Palliative care is defined as that which addresses 'the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering' [17] pp84. While a palliative approach can be used in the management of life limiting conditions during the acute, chronic or terminal phases, the term 'end-of-life care' is commonly taken to refer to care provided in the final phase of life [3,5]. Additionally, supportive care is an umbrella term which encompasses palliative care and focuses on helping the consumer, family and provider in coping with the condition 'from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease' [9]. Regardless of the nomenclature, individuals with end-stage COPD have limited access to supportive palliative services despite experiencing similar yet more severe symptoms than those with malignant disease [3,18,19]. Integrating these philosophical approaches in care provision is more challenging. Based upon the review of the management of chronic illness, The Chronic Care Model has been shown to be useful in addressing the burden of chronic disease [17]. This approach for reform, that focuses on the patient and their family at the centre of care, supported by enabling policy and care coordination, was used as a unifying framework to organise issues emerging from the review and to develop priorities for further research [17,20].

International policy documents indicate the need for individuals to have access to supportive and palliative services regardless of underlying diagnosis, and in particular for those who have non-malignant terminal conditions [8,10,17,21]. However, this rhetoric will require reengineering of work practice, health care organisation and the ways in which health professionals and consumers view palliative care [22]. Priorities for research must work to develop and evaluate

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effective health service models for end-stage COPD [8,23]. Specifically the key priorities for research around end-stage COPD should address developing:

- evidence for a systems approach to non-malignant palliative care, such as that seen in national programs such as The 'Promoting Excellence in End-of-life Care Program' and the 'End-of-life Programme' [21,24];
- advance care planning and training of providers in undertaking advance care planning [25-27];
- evidence based decision pathways to assist providers, consumers and their families in accessing health services [1,27,28]; and
- more effective strategies for symptom management, particularly breathlessness [2-5,25,29].

Systems Approach to Non-Malignant Palliative Care

The fluctuating and episodic decline of COPD is seen as a key barrier to providing palliative care services, to which access remains limited in this patient group [4,5,29,30]. The complexity and severity of symptoms experienced by patients with end-stage COPD highlights the need for a systems approach to palliation, such as those outlined in the 'Promoting Excellence in End-of-life Care Program' in the USA, the 'End-of-life Programme' in the United Kingdom, and in organising frameworks such as the Chronic Care Model [8,21,23,24].

Although literature concerning discrete elements of end-stage COPD management is present, such as pharmacological and non-pharmacological interventions [11-13], there are limited data which discusses the comprehensive and collaborative approaches required to address the complex and multivariate needs of patients with end-stage COPD [6,31]. These needs extend beyond the patients to caregivers [7,20]. A systems based method, integrating a palliative approach, would ideally allow for active management to be combined with planning for the final stages of life and encourage collaboration and continuity across health services [6,8,10,17,23,31-33]. Programs such as the 'Promoting Excellence in End-of-life Care Program' in the USA and the 'End-of-life Programme' in the United Kingdom have been successful in integrating palliative care for non-malignant conditions within the health system and increased the provision of high-quality palliative care to a broader range of patient groups [8,21,24]. Research is required to strengthen the evidence for a systems approach to managing end-stage COPD across a variety of settings, from primary to acute care [23].

Prioritisation of Advance Care Planning and Training of Providers

Communication around end-of-life should be commenced early to ensure that individuals are able to articulate their wishes and goals in approaching the final stages of life [14,25,34]. The fluctuations in the disease trajectory and speed at which patients can deteriorate into the terminal phase strengthens the argument for early advance care planning in patients with end-stage COPD in particular [5].

Providers do acknowledge that the majority of patients with end-stage COPD are unaware of the terminal nature of their condition [26,35]. Furthermore, providers acknowledge the need for timely advance care planning [4,26,35]. Building the capacity of patients and providers to engage in advance care planning is required for this to occur [10,14,22,28].

Providers' confidence in undertaking end-of-life discussions would improve through training in: techniques for initiating discussion; the content which patients' value; and what services are available to end-stage COPD patients [10,22]. Better understanding for patients and providers, and the use of a unifying framework such as the Chronic Care Model, would assist in the early implementation of system interventions and advance care planning that support patients through the palliative phase of their disease [10,22,23].

Development of Decision Pathways

Emerging from the review is the high symptom burden experienced by patients with end-stage COPD and the failure of current management systems to relieve suffering [2-4,23]. Clinical pathways are standardised, evidence-based multidisciplinary management plans that identify the sequence of assessment and clinical interventions within a framework [27]. They provide a mechanism for decision support and timeframes for expected outcomes for clinical conditions. Considering the complexity and variability of end-stage COPD, it is difficult for providers and consumers to react with confidence to ever changing symptoms and maintain confidence in management decisions when faced with unremitting symptoms [8,27]. Evaluating such an approach may assist in symptom management. For example clinical pathways that identify early deterioration, provide decision support and facilitate referral to appropriate providers may be of use in avoiding unnecessary episodes of respiratory failure [25,27].

Prospective and systematic development of innovative, interdisciplinary interventions may allow for evidence based pathways that address the physical, psychological and social issues associated with end-stage COPD [9,10,27]. Implementation of clinical pathways that incorporate aspects of evidence based pharmacological and non-pharmacological strategies, and self-management support may be of use in both community and acute healthcare settings [8-10,23,27].

Conclusion

To date the literature in end-stage COPD is more replete with challenges rather than solutions. Emerging from this review is the importance of adequately powered clinical trials to not only address clinical management but also health services planning and evaluation of Models of care. Models that incorporate policy makers, providers, consumers and their families in effective care provision are an important strategy to address the increasing numbers of individuals dying with COPD.

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