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 approach 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 effective health care interventions, particularly in the context of an aging population who commonly present with multiple chronic conditions [1].
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

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 unrelenting 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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