

End-of-life care for persons with advanced chronic obstructive pulmonary disease: Report of a national interdisciplinary consensus meeting

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While systemic shortcomings in meeting the needs of individuals with progressive chronic illnesses at the end of life have been well documented, there is growing interest in improving both care and quality of life for persons with advanced chronic obstructive pulmonary disease (COPD). For instance, the American Thoracic Society has issued an official statement on palliative care for patients with respiratory diseases, affirming that the prevention, relief, reduction and soothing of symptoms "without affecting a cure" must become an integral component of standard care. A recent Medline search located 1015 articles related to palliative or end-of-life care for people with COPD published between 2001 and 2008, compared with only 336 articles published before 2001. To address the needs of Canadian patients, an interdisciplinary consensus meeting, funded by the Canadian Institutes of Health Research and supported by the Canadian Thoracic Society, the Canadian Respiratory Health Professionals and the Canadian Lung Association was convened in Toronto, Ontario, on November 22, 2008, to begin examining the quality of end-of-life care for individuals with COPD in Canada. The present report summarizes the background to and outcomes of this consensus meeting.

Key Words: *Chronic obstructive pulmonary disease; COPD; End-of-life care*

While systemic shortcomings in meeting the needs of individuals with progressive chronic illnesses at the end of life have been well-documented, there is growing interest in improving both care and quality of life for persons with advanced chronic obstructive pulmonary disease (COPD) (1). In fact, the American Thoracic Society has issued an official statement on palliative care for patients with respiratory diseases (2).

Individuals with advanced COPD experience poor quality of life and high levels of symptom burden typically including intractable dyspnea (3-7), fatigue (5,8-11), significant disability (4-6,9,12,13), social isolation (9,10,12-14), and high levels of anxiety and depression (4,11,15). The caregiving burden for family members of people with advanced COPD is significant (13,16-18), particularly given the lack of resources available to support individuals with chronic illness in the community (5,8,10).

Soins de fin de vie pour les personnes atteintes de maladie pulmonaire obstructive chronique avancée : Rapport d'une réunion consensuelle interdisciplinaire nationale

Si on a bien documenté les lacunes de nature systémique qui nous empêchent de répondre adéquatement aux besoins des personnes atteintes de maladie chronique progressive en fin de vie, on note un intérêt croissant pour l'amélioration des soins et de la qualité de vie des patients qui souffrent de maladie pulmonaire obstructive chronique (MPOC) avancée. Par exemple, l'American Thoracic Society a émis un énoncé de position officiel sur les soins palliatifs à l'intention des personnes atteintes de maladie respiratoire selon lequel la prévention, le soulagement, l'atténuation et l'apaisement des symptômes (« sans objectif de guérison ») doivent faire désormais partie intégrante des soins standard. Une récente interrogation de la base de données MEDLINE a permis de recenser 1 015 articles ayant trait aux soins palliatifs ou de fin de vie des personnes souffrant de MPOC publiés entre 2001 et 2008, comparativement à 336 articles seulement publiés avant 2001. Pour combler ce besoin au Canada, une réunion consensuelle pluridisciplinaire, rendue possible grâce aux Instituts de recherche en santé du Canada et appuyée par la Société canadienne de thoracologie, les Professionnels canadiens en santé respiratoire et l'Association pulmonaire, a eu lieu à Toronto, en Ontario, le 22 novembre 2008 pour amorcer une analyse de la qualité des soins palliatifs chez les personnes souffrant de MPOC au Canada. Le présent rapport résume l'historique et l'issue de cette réunion consensuelle.

In spite of the many unmet needs of patients with advanced COPD and their caregivers, disparities in access to specialized palliative care services at the end of life between patients with COPD and those with lung cancer have been widely reported (4,19,20). Reasons for these disparities include 'prognostic paralysis', in which clinicians of patients with uncertain illness trajectories (such as COPD) procrastinate when considering the need for palliative care services; patient unwillingness to discuss end-of-life care (21,22); provider discomfort with initiating end-of-life dialogues (21); lack of financial resources (23); and lack of clinicians with expertise in the management of nonmalignant disease (23). Finally, the relative lack of evidence regarding the impact of incorporating palliative approaches into the care of people with advanced COPD (20) suggests that significant gaps in our knowledge base and, hence, patient management, remain.

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TABLE 1

Consensus statements regarding process indicators of quality of end-of-life care**1. Initiating the dialogue and end-of-life care planning**

- Clinicians should ensure that end-of-life care planning (which may include the completion of advance directives) occurs in a culturally safe manner for all patients with serious illness. End-of-life care planning should include dialogue about surrogate decision-makers, resuscitation, emergency treatment (including intubation) and ongoing mechanical ventilation, and be initiated as early as possible in the course of the illness before the end of life (American College of Physicians)
- End-of-life care planning may be initiated at diagnosis, if appropriate, to the patient's circumstances. Additional triggers for end-of-life care planning include situations in which there is serious impairment of functional status, the patient is asking questions salient to the end of life or when the provider would not be surprised if the patient died in the following 12 months
- The topic of end-of-life care planning should be first introduced by the health care provider most trusted by the patient, although physician involvement in the decision-making process is crucial. Families and significant others play a pivotal role in planning for the end of life of people with advanced COPD. The involvement of and ongoing dialogue with family members and significant others in end-of-life care planning needs to be strongly encouraged by providers

2. Anticipating the need for end-of-life care

- While accurate prediction of the trajectory of decline for a given individual with advanced COPD is challenging, the primary indicators that the patient is approaching the end of life are: a) poor functional status (Medical Research Council dyspnea scale 4 to 5); b) severe acute exacerbation; c) FEV₁ less than 30% predicted; d) signs of respiratory failure or pulmonary hypertension; e) body mass index of less than 20 kg/m²; or f) the patient is starting to wish for or talk about death. Deteriorating psychosocial/cognitive status and a pattern of increasing health care utilization are also useful indicators. Ongoing and focused monitoring (including the use of functional status scales such as the Palliative Performance Scale and the Bode Index) have prognostic value and should be used in both inpatient and home care settings

3. Advocating for patient and caregiver preferences as to the site of end-of-life care

- The specific location of both care and death is less important for persons with advanced COPD than implementing end-of-life care in a setting of their choice that accommodates both the patient's and caregiver's unique needs and preferences. The ability to access both inpatient and home support is a critical indicator of the quality of end-of-life care for people with advanced COPD. Alternative settings such as day hospices that may supplement care and relieve caregiver burden need to be explored

4. Optimizing interdisciplinary team care

- End-of-life care is optimized through continuity of direct care providers and access to an interdisciplinary team. Knowledgeable family physicians, nurse practitioners and case managers are the foundation of quality end-of-life care. Family physicians and home care teams should have access to the resources of both respiratory disease specialists and palliative care teams
- Enhanced collaboration among respiratory care providers and palliative care services will optimize quality of care. While palliative care specialists have an important role in consulting to provide symptom management, family physicians, respiratory specialists and home care providers must be trained to provide quality end-of-life care. Patients and families need clarification about the roles of each team member
- Specific initiatives designed to optimize end-of-life care for people with advanced COPD must be evaluated. These initiatives include 24 h emergency response teams for community-based patients (including same-day in-home response), dedicated case managers, system navigator models, rapid access to respite and palliative care beds in nursing homes and hospitals, and access to outpatient symptom management clinics. A strong evidence base, generated by high-quality research for best practices in end-of-life care for this population, must be supported by appropriate and sustainable funding

5. Selecting interventions for patients with advanced COPD

- Subjective symptom assessments (eg, Edmonton Symptom Assessment Scale) need to be routinely conducted in a consistent manner. Multidisciplinary interventions must address the whole person and include psychosocial, spiritual and existential dimensions. Screening for depression, fatigue, anxiety and caregiver burden, as well as appropriate interventions to alleviate these concerns, are critical. The use of opioids to manage dyspnea at the end of life may be a beneficial intervention. Interventions designed to enhance exercise tolerance, nutritional status or treat infection must be considered
- Interventions that may be detrimental to the quality of life of people with advanced COPD include sustained mechanical ventilation, 'emergency decisions' about life-sustaining therapies and cardiopulmonary resuscitation

COPD Chronic obstructive pulmonary disease; FEV₁, Forced expiratory volume in 1 s

Calls for a new model of care for people with advanced COPD, in which comprehensive palliative approaches are embedded within standard respiratory care, are becoming increasingly frequent (2,24,25). The commitment to high-quality care at the end of life is underpinned by a responsibility to evaluate and improve this care. Quality indicators (explicitly defined and measurable items referring to the structures, processes or outcomes of care [26]) are one means by which to evaluate end-of-life care quality that have been previously used with cancer populations (27-29). The primary focus at the Canadian consensus meeting was to discuss the applicability, development and monitoring of indicators measuring the quality of end-of-life care for individuals with advanced COPD.

The impetus for organizing this meeting was provided by the work two of the authors (DG, DM) had previously undertaken using administrative data to examine health care use of people with COPD who were in their last 12 months of life. Funding for the meeting was secured through a Canadian Institutes of Health Research Meetings, Planning and Dissemination Grant. Along with representatives from the Canadian Lung Association, the Canadian Thoracic Society,

the Canadian Respiratory Health Professionals and the Canadian Hospice and Palliative Care Association (CHPCA), patients with COPD and their family members – an interdisciplinary, nationally representative group of professionals with an interest in end-of-life care for this population – were invited to participate in this initial one-day meeting.

MEETING OUTCOMES

Based on the findings of a preliminary Delphi survey conducted by DG (methodology and findings to be reported elsewhere) and designed to develop a draft of end-of-life care quality indicators for persons with COPD, a set of eight statements formed the basis for the group's discussion. The initial statements were revised using consensus methods. Five statements (Table 1) emerged to reflect group opinion regarding critical process and outcome indicators of quality end-of-life care for individuals with advanced COPD (Table 2).

FUTURE PLANS

Participants at the meeting agreed to move forward with an agenda to enhance end-of-life care for people with advanced

TABLE 2
Consensus statements regarding outcome indicators of quality of end-of-life care for persons with advanced chronic obstructive pulmonary disease

- Symptom control is the most critical indicator of quality of end-of-life care. For this population, the symptoms of dyspnea, pain, depression, fatigue, anxiety and fear must be considered
- Both system and patient-centred measures provide additional information about how well we are caring for people dying from advanced chronic obstructive pulmonary disease. These include measures of:
 - Continuity of care;
 - Informal caregiver burden;
 - Patient and family satisfaction with care;
 - Quality of life during the months or years the person is living with advanced disease; and
 - Timely, accurate communication between patients, caregivers and providers. Further investigation must occur to determine how to best measure each of these indicators and how to incorporate them into practice

COPD. Strategies to accomplish this goal were identified and include validating the indicators emerging from this meeting with patients and families across the country, developing a national position statement on end-of-life care for this population, collaborating with the CHPCA to enhance training of respiratory professionals in end-of-life care using an established workshop format, promoting joint initiatives between respiratory professionals and the CHPCA, exploring the possibilities of purchasing items on representative national surveys that reflect lung health concerns and working toward monitoring selected key indicators on a national basis. To continue work on these initiatives, a Respiratory End-of-life Care Collaborative Group will be developed. Interested individuals may contact Donna Goodridge at donna.goodridge@usask.ca for further information regarding activities of the group.

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