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ORIGINAL ARTICLE

End-of-life care in COPD: A survey carried out with Portuguese Pulmonologists[☆]



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KEYWORDS

COPD; Palliative care; End-of-life; Communication

Abstract

Introduction: End-of-life (EoL) care is a major component in the management of patients with advanced COPD. Patient-physician communication is essential in this process.

Aim: To evaluate the practice of Portuguese Pulmonologists in EoL communication and palliative care in COPD.

Methods: An on-line survey was sent to physicians affiliated to the Portuguese Pneumology Society.

Results: We obtained 136 answers from 464 eligible participants (29.3%). About half of the physicians reported that they have rarely introduced EoL discussions with their COPD patients (48.5%). Most had never/rarely suggested decision-making on the use of invasive mechanical ventilation (68.4%). Discussions were described as occurring mostly during/after a major exacerbation (53.7%). Only 37.5% of participants reported treating dyspnoea with opioids frequently/always. Only 9.6% stated that they never/rarely treated anxiety/depression. Most participants perceive the discussion of EoL issues as being difficult/very difficult (89.0%). The reasons most frequently given were feeling that patients were not prepared for this discussion (70.0%), fear of taking away a patient's hope (58.0%) and lack of training (51.0%).

Conclusion: Patient and medical staff EoL communication in COPD is still not good enough. Training in this area and the creation of formal protocols to initiate EoL have been identified as major factors for improvement.

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PALAVRAS-CHAVE

DPOC; Cuidados paliativos; Fim de vida; Comunicação

Assistência a doentes terminais com DPOC: um inquérito realizado a Pneumologistas Portugueses

Resumo

Introdução: Os cuidados terminais (EoL) são um componente importante do tratamento de doentes com doença pulmonar obstrutiva crónica (DPOC) avançada. A comunicação entre o doente e o médico é fundamental neste processo.

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Objetivo: Avaliar a prática dos pneumologistas portugueses na comunicação sobre o fim de vida e os cuidados paliativos na DPOC.

Métodos: Foi enviado um inquérito online para os médicos sócios da Sociedade Portuguesa de Pneumologia.

Resultados: Recebemos 136 respostas dos 464 participantes elegíveis (29,3%). Cerca de metade dos médicos indicaram que raramente iniciaram conversas sobre o fim de vida com os seus doentes com DPOC (48,5%). A maioria nunca/raramente sugeriram a toma de decisão sobre a utilização de ventilação mecânica invasiva (68,4%). As conversas foram descritas como ocorrendo, na sua maioria, durante/após uma exacerbação grave (53,7%). Apenas 37,5% dos participantes indicaram tratar a dispneia frequentemente/sempre com opiáceos. Apenas 9,6% indicaram que nunca/raramente trataram a ansiedade/depressão. A maioria dos participantes considerou a conversa sobre questões de fim de vida como sendo difícil/muito difícil (89,0%). Os motivos mais frequentemente indicados foram a sensação de que os doentes não estavam preparados para essa conversa (70,0%), medo de tirar a esperança aos doentes (58,0%) e falta de formação (51,0%).

Conclusão: A comunicação sobre o fim de vida entre o doente e os médicos na DPOC ainda não é suficientemente boa. A formação nesta área e a criação de protocolos formais para iniciar os cuidados em fim de vida foram identificados como fatores importantes a melhorar.

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Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic and progressive disease that in its advanced stages may be associated with important physical, psychological and social impairments. Palliative care should be provided to advanced COPD patients so as to reduce the high burden of chronically debilitating symptoms such as dyspnoea and anxiety.

Patient-physician communication on prognosis, preferences for life-sustaining treatments and palliative care, is essential to ensure that COPD patients receive end-of-life (EoL) quality care that is consistent with the values upheld. The uncertain disease trajectory, which frequently involves unexpected deterioration in health status, makes planning of care in advance essential.¹

In recent years, there has been a growing interest in EoL care in advanced COPD. Some important scientific societies have published recommendations on this theme and the *Global Initiative for Obstructive Pulmonary Disease* (GOLD) introduced it for the first time into the 2013 updated revision.^{2–4} The challenge remains in how EoL care is implemented in practice. At present, there is evidence that COPD patients receive poor EoL care and that there is insufficient patient-physician discussion on EoL preferences.^{5,6}

We developed a survey to characterize the Portuguese Pulmonologists' practice in EoL communication and palliative care in advanced COPD patients, and identify hurdles to its consistent implementation. With this study, we hope to help establish strategies to overcome the difficulties that physicians face in their every-day practice, which ultimately may lead to an improvement on the EoL care that COPD patients receive.

Methods

Participant recruitment

In January 2013 we asked the Portuguese Pneumology Society (SPP) to provide us with the mailing list of all affiliated

Respiratory Medicine specialists and fellows with email contact. We obtained a list of 464 members. We only asked physicians who had had clinical activity in the previous year to answer the survey.

Questionnaire development and administration

A self-administrated questionnaire was developed specifically for this study. The authors generated questions based on a review of the literature. Questions were drawn up to address four main themes: (1) palliation of symptoms; (2) frequency and topics of EoL communication; (3) timing and interveners of EoL communication; (4) obstacles to EoL communication.

The following data were collected to characterize participants: age, gender, religious beliefs, years of practice, type of institution, region of the country and number of patients with COPD treated per year.

At the beginning of the questionnaire, participants were asked to answer questions with reference to the patients they had treated in the previous year, who had two or more of the following characteristics: forced expiratory volume in first second (FEV1) under 30%, oxygen dependence, one or more hospital admissions in the previous year for an acute exacerbation of COPD, left heart failure or other comorbidities, weight loss or caquexia, decreased functional status, increasing dependence on others and were over 70 years old. We adopted these criterion from Curtis, whose purpose was to identify patients in whom a discussion on preferences about EoL care should be initiated.⁵

We pretested the questionnaire on a convenience sample of 6 pulmonologists to ensure clarity and comprehensiveness. A web platform was then designed to facilitate survey completion and data collection. Participants received an invitation to answer the questionnaire via an e-mail sent by the SPP, containing a link to the online platform. One month was allowed for questionnaire completion. During the one month period two e-mails of reminder were sent to each

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