

Editorial



Cite this article: Gonçalves B, Harkess-Murphy E, Cund A, Sime C, Lusher J (2024). COPD patients' accessibility to palliative care: Current challenges and opportunities for improvement. *Palliative and Supportive Care* **22**, 429–431. <https://doi.org/10.1017/S1478951524000063>




Received: 30 November 2023

Accepted: 25 December 2023

Corresponding author: Barbara Gonçalves;
Email: barbara.goncalves@ensp.unl.pt

COPD patients' accessibility to palliative care: Current challenges and opportunities for improvement

Barbara Gonçalves, PH.D.^{1,2} , Eileen Harkess-Murphy, PH.D.³ ,

Audrey Cund, PH.D.⁴ , Caroline Sime, PH.D.⁵  and Joanne Lusher, PH.D.⁶ 

¹School of Health and Life Sciences, University of the West of Scotland - Lanarkshire Campus, Hamilton, UK; ²NOVA National School of Public Health, Public Health Research Center, Comprehensive Health Research Center, CHRC, NOVA University Lisbon, Lisbon, Portugal; ³School of Health and Life Sciences, University of the West of Scotland, Paisley, UK; ⁴School of Health and Life Sciences, University of the West of Scotland - Ayr Campus, Ayr, UK; ⁵Scottish Partnership for Palliative Care, Edinburgh, UK and ⁶Provost's Group, Regent's University London, London, UK

Chronic obstructive pulmonary disease (COPD) is a progressive lung condition which ranks as the third leading cause of death worldwide (Celli et al. 2022; World Health Organization 2023). Advanced stages of COPD are associated with substantial symptom burden and reduced quality of life (QOL) (Melhem et al. 2021). Contact with health services for people with COPD usually consists of visits by a primary care team, including general practitioners and nurses, as well as emergency hospital admissions that are prompted by disease exacerbations (Elkington et al. 2005). However, access to other specialist forms of support, such as palliative care, is often inaccessible for individuals with COPD (Beernaert et al. 2013; Goodridge et al. 2008; Rosenwax et al. 2016; Rush et al. 2017).

Palliative care should be available for patients with COPD to focus on managing their condition in holistic ways which can lead to an improvement in QOL with effective communication and psychosocial support for carers and patients. It is essential to focus on symptom-related treatment, given the high prevalence of physical symptoms and distress connected to COPD, with palliative care interventions having promise of substantial benefits (Blinderman et al. 2009).

Indeed, the impact of palliative care interventions on patients' sense of mastery, especially in alleviating breathlessness, highlights the importance of a holistic approach to symptom management and the provision of psychosocial support (Higginson et al. 2014). Early integration of palliative care, with its person- and team-centered approach, may prove valuable for patients with COPD, thus enhancing their understanding and acceptance of the condition, whilst living according to their physical capabilities with improved psychosocial support (Marx et al. 2016).

While palliative care services are available for people with COPD, research suggests that they are not effectively utilized by individuals with COPD (Halpin 2018; Inbadas et al. 2018). The concern surrounding insufficient palliative care for people with COPD was initially reported in a study with COPD patients with lung cancer (Gore et al. 2000). Since then, literature has consistently emphasized the low accessibility of palliative care services and the unmet needs of patients in end-of-life care (Halpin 2018; Schroedl et al. 2014; Vermeylen et al. 2015). For example, Bloom et al. (2018) analyzed records from 2004–2015 of deceased individuals and found that only 21.4% of them received palliative care, with less than half receiving any within the last 6 months of their lives and a third in the last month before death. The study also shed light on a significant pattern that emerged of patients diagnosed with both COPD and lung cancer were 40% more likely to receive palliative care than those with COPD alone.

Previously, it was implied that patients with COPD were referred more commonly to palliative care due to an underlying cancer diagnosis, not COPD (Meffert et al. 2015). In any case, there has been progressive use of palliative care over recent year which highlights a need to improve all aspects of palliative care services (Bloom et al. 2018). Regardless of the considerable burden of COPD, the absence of formal guidelines for palliative care implementation remains evident (Halpin 2018). Moreover, despite the growing need for palliative care, national health policies do not explicitly prioritize palliative and end-of-life care (Sleeman et al. 2019, 2021). Nevertheless, it is recommended that all clinicians overseeing patients with COPD should be well-versed in the adequacy of palliative care for symptom management and should integrate palliative care into their practice (Vogelmeier et al. 2017). Consequently, there is a critical need for guidance that promotes early palliative care, ensuring that individuals with end-stage COPD and their caregivers have access to the full range of services offered by multidisciplinary palliative care teams (Strutt 2020).

Research has identified that early use of palliative care is recommended alongside disease-oriented care to avoid prognosis paralysis (Epiphanou *et al.* 2014). However, identifying the most suitable timing for transition to palliative care can be somewhat challenging and unclearly defined (Murray *et al.* 2005). The conventional model of care for patients with advanced diseases, like COPD, is established on a foundation that involves an abrupt shift from life-sustaining care to palliative care, but this may not be suitable for patients with COPD (Spathis and Booth 2008). One reason for this is that COPD has no apparent onset, the timing of death is unpredictable, and it is challenging to decide on the time for the transition (Casanova *et al.* 2011; Giacomini *et al.* 2012; Pinnock *et al.* 2011). Indeed, palliative care implementation should be started on the presence of refractory symptoms, patients expressing specific preferences, and those who have unmet needs (Rajnovanu *et al.* 2020). Furthermore, planning decisions regarding a patient's end-of-life care is recommended when indicators permit the identification of an estimated survival of less than 6 to 12 months (Braço Forte and Sousa 2017).

Palliative care, often mistaken as exclusively end-of-life care by patients, caregivers, and healthcare professionals, contributes significantly to the underutilization of these services for COPD patients (Smallwood *et al.* 2018). A lack of awareness among physicians about the palliative care aspects for patients with COPD stands as a prevalent factor contributing to the unmet needs of this population (Meffert *et al.* 2015). Another potential reason for delayed transition to palliative care is that health and social services flounder to recognize the problem of breathlessness to address it appropriately (Gysels and Higginson 2008; Hasson *et al.* 2008). There remains a lack of expertise in managing this symptom by health and social care workers, which, in turn, discourages patients from sharing complaints as they often feel ignored (Gysels and Higginson 2008). This is further exacerbated by the premise that healthcare professionals have insufficient information or training about this (Nurmatov *et al.* 2012).

This editorial exposes that despite the potential benefits of palliative care, its application in COPD remains inadequately addressed. Individuals with advanced COPD experience comparatively low access to palliative care services. Studies reveal a growing awareness of the importance of palliative care, emphasizing the need for improved services beyond end-of-life treatment. Recognizing the suitable timing for palliative care transition is challenging due to the unpredictable progression of COPD. Furthermore, the underrecognition of palliative care requirements is specific to COPD and insufficient expertise in managing symptoms, especially breathlessness, further hinder access to appropriate care. To address these challenges, we advocate for a shift in approach and practice that is underpinned by education and training and tailored directly to the individual needs of patients and their families. Finally, this emphasizes that broader policies for symptom management and referral are essential to ensure timely and comprehensive palliative care provision for patients with COPD.

Competing interests. The authors declare no potential conflict of interest.

References

Bearnaert K, Cohen J, Deliens L, *et al.* (2013) Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory Medicine* 107(11), 1731–1739. doi:10.1016/j.rmed.2013.06.003

- Blinderman CD, Homel P, Billings JA, *et al.* (2009) Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *Journal of Pain and Symptom Management* 38(1), 115–123. doi:10.1016/j.jpainsymman.2008.07.006
- Bloom CI, Slaich B, Morales DR, *et al.* (2018) Low uptake of palliative care for COPD patients within primary care in the UK. *European Respiratory Journal* 51(2), 1701879. doi:10.1183/13993003.01879-2017
- Braço Forte C and Sousa S (2017) End of life in COPD patients: Time for a change. *Breathe (Sheff)* 13(4), e84–e86. doi:10.1183/20734735.013617
- Casanova C, de Torres JP, Aguirre-Jaime A, *et al.* (2011) The progression of chronic obstructive pulmonary disease is heterogeneous: The experience of the BODE cohort. *American Journal of Respiratory and Critical Care Medicine* 184(9), 1015–1021. doi:10.1164/rccm.201105-0831OC
- Celli B, Fabbri L, Criner G, *et al.* (2022) Definition and nomenclature of chronic obstructive pulmonary disease: Time for its revision. *American Journal of Respiratory and Critical Care Medicine* 206(11), 1317–1325. doi:10.1164/rccm.202204-0671PP
- Elkington H, White P, Addington-Hall J, *et al.* (2005) The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine* 19(6), 485–491. doi:10.1191/0269216305pm1056oa
- Epiphanou E, Shipman C, Harding R, *et al.* (2014) Avoid 'prognostic paralysis'—just get ahead and plan and co-ordinate care. *NPJ Primary Care Respiratory Medicine* 24(1), 14085. doi:10.1038/npjpcrm.2014.85
- Giacomini M, DeJean D, Simeonov D, *et al.* (2012) Experiences of living and dying with COPD: A systematic review and synthesis of the qualitative empirical literature. *Ontario Health Technology Assessment Series* 12(13), 1–47.
- Goodridge D, Lawson J, Duggleby W, *et al.* (2008) Health care utilization of patients with chronic obstructive pulmonary disease and lung cancer in the last 12 months of life. *Respiratory Medicine* 102(6), 885–891. doi:10.1016/j.rmed.2008.01.007
- Gore JM, Brophy CJ and Greenstone MA (2000) How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 55(12), 1000–1006. doi:10.1136/thorax.55.12.1000
- Gysels M and Higginson IJ (2008) Access to services for patients with chronic obstructive pulmonary disease: The invisibility of breathlessness. *Journal of Pain and Symptom Management* 36(5), 451–460. doi:10.1016/j.jpainsymman.2007.11.008
- Halpin DMG (2018) Palliative care for people with COPD: Effective but underused. *European Respiratory Journal* 51(2), 1702645. doi:10.1183/13993003.02645-2017
- Hasson F, Spence A, Waldron M, *et al.* (2008) I can not get a breath: Experiences of living with advanced chronic obstructive pulmonary disease. *International Journal of Palliative Nursing* 14(11), 526–531. doi:10.12968/ijpn.2008.14.11.31756
- Higginson IJ, Bausewein C, Reilly CC, *et al.* (2014) An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial. *Lancet Respiratory Medicine* 2(12), 979–987. doi:10.1016/s2213-2600(14)70226-7
- Inbadas H, Carrasco JM, Gillies M, *et al.* (2018) The level of provision of specialist palliative care services in Scotland: An international benchmarking study. *BMJ Support Palliative Care* 8(1), 87–92. doi:10.1136/bmjspcare-2016-001301
- Marx G, Nasse M, Stanze H, *et al.* (2016) Meaning of living with severe chronic obstructive lung disease: A qualitative study. *BMJ Open* 6(12), e011555. doi:10.1136/bmjopen-2016-011555
- Meffert C, Hatami I, Xander C, *et al.* (2015) Palliative care needs in COPD patients with or without cancer: An epidemiological study. *European Respiratory Journal* 46(3), 663–670. doi:10.1183/09031936.00208614
- Melhem O, Savage E and Lehane E (2021) Symptom burden in patients with chronic obstructive pulmonary disease. *Applied Nursing Research* 57, 151389. doi:10.1016/j.apnr.2020.151389
- Murray SA, Boyd K and Sheikh A (2005) Palliative care in chronic illness. We need to move from prognostic paralysis to active total care. *BMJ* 330(7492), 611–612. doi:10.1136/bmj.330.7492.611

- Nurmatov U, Buckingham S, Kendall M, et al.** (2012) Effectiveness of holistic interventions for people with severe chronic obstructive pulmonary disease: Systematic review of controlled clinical trials. *PLoS One* 7(10), e46433. doi:10.1371/journal.pone.0046433
- Pinnock H, Kendall M, Murray SA, et al.** (2011) Living and dying with severe chronic obstructive pulmonary disease: Multi-perspective longitudinal qualitative study. *BMJ* 342, d142. doi:10.1136/bmj.d142
- Rajnoveanu RM, Rajnoveanu AG, Fildan AP, et al.** (2020) Palliative care initiation in chronic obstructive pulmonary disease: Prognosis-based, symptoms-based or needs-based? *International Journal of Chronic Obstructive Pulmonary Disease* 15, 1591–1600. doi:10.2147/copd.S254104
- Rosenwax L, Spilsbury K, McNamara BA, et al.** (2016) A retrospective population based cohort study of access to specialist palliative care in the last year of life: Who is still missing out a decade on? *BMC Palliative Care* 15(1), 46. doi:10.1186/s12904-016-0119-2
- Rush B, Hertz P, Bond A, et al.** (2017) Use of palliative care in patients with end-stage COPD and receiving home oxygen: National trends and barriers to care in the United States. *Chest* 151(1), 41–46. doi:10.1016/j.chest.2016.06.023
- Schroedl CJ, Yount SE, Szmuilowicz E, et al.** (2014) A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease. A potential role for specialist palliative care? *Annals of the American Thoracic Society* 11(9), 1433–1438. doi:10.1513/AnnalsATS.201404-155BC
- Sleeman KE, de Brito M, Etkind S, et al.** (2019) The escalating global burden of serious health-related suffering: Projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health* 7(7), e883–e892. doi:10.1016/s2214-109x(19)30172-x
- Sleeman KE, Timms A, Gillam J, et al.** (2021) Priorities and opportunities for palliative and end of life care in United Kingdom health policies: A national documentary analysis. *BMC Palliative Care* 20(1), 108. doi:10.1186/s12904-021-00802-6
- Smallwood N, Currow D, Booth S, et al.** (2018) Attitudes to specialist palliative care and advance care planning in people with COPD: A multi-national survey of palliative and respiratory medicine specialists. *BMC Palliative Care* 17(1), 115. doi:10.1186/s12904-018-0371-8
- Spathis A and Booth S** (2008) End of life care in chronic obstructive pulmonary disease: In search of a good death. *International Journal of Chronic Obstructive Pulmonary Disease* 3(1), 11–29. doi:10.2147/copd.s698
- Strutt R** (2020) When to refer patients with advanced COPD to palliative care services. *Breathe* 16(3), 200061. doi:10.1183/20734735.0061-2020
- Vermeylen JH, Szmuilowicz E and Kalhan R** (2015) Palliative care in COPD: An unmet area for quality improvement. *International Journal of Chronic Obstructive Pulmonary Disease* 10, 1543–1551. doi:10.2147/copd.S74641
- Vogelmeier CF, Criner GJ, Martinez FJ, et al.** (2017) Global strategy for the diagnosis, management, and prevention of chronic obstructive lung disease 2017 Report. GOLD Executive Summary. *American Journal of Respiratory and Critical Care Medicine* 195(5), 557–582. doi:10.1164/rccm.201701-0218PP
- World Health Organization** (2023) Chronic obstructive pulmonary disease (COPD). [https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-\(copd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-(copd)) (accessed 26 September 2023).