J Hosp Palliat Care 2025 March;28(1):25-29
https://doi.org/10.14475/jhpc.2025.28.1.25

Brief Communication

pISSN 2765-3072 • eISSN 2765-3080

Palliative Care in End-Stage Lung Disease

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The prevalence of chronic obstructive pulmonary disease (COPD) is increasing, and the condition is associated with a high mortality rate. For patients with COPD, the reality of a life-limiting illness causing severe breathlessness is often daunting. Unlike cancer, the progression of COPD is less predictable, making its prognosis challenging for clinicians. Patients with COPD in the intensive care unit (ICU) present a unique set of challenges characterized by persistent respiratory distress, dependence on ventilator support, and complex medical needs. Therefore, palliative care is vital for ICU patients with COPD, as it offers a compassionate, patient-centered approach that emphasizes symptom relief, quality of life, and alignment of care with patient values. However, palliative care for these patients is extremely difficult in Korea. Discussion of end-of-life care for non-cancer patients is particularly difficult in Korean society. One reason for this is that hospice palliative care is perceived as termination of treatment by the public. Additionally, because Korean society has a Confucian cultural background, people are usually reluctant to discuss death. Moreover, lack of attention among medical professionals is another key factor that makes implementing palliative care difficult for patients with end-stage COPD. This review aimed to explore ways to provide a meaningful and dignified life for patients with COPD in the ICU by administering palliative care.

Key Words: Chronic obstructive pulmonary disease, Hospice care, Palliative care

Received November 1, 2024
Revised February 13, 2025
Accepted February 14, 2025

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Funding/Support
This study was supported by a grant from the National R & D Program for cancer control, Ministry of health & welfare, Republic of Korea (RS-2023-CC140333).

INTRODUCTION

Similar to other patients with end-stage cancer, those with non-cancer end-stage illnesses experience severe symptoms and discomfort. However, unlike cancer, the onset and progression of most non-cancer end-stage diseases are often ambiguous, making it more challenging to predict the end of life [1-3]. Recent guidelines recommend the initiation and integration of palliative respiratory care in adult patients with chronic obstructive pulmonary disease (COPD). This provides opportunities for patients and their families to benefit from hospice and palliative care at an early stage [4-6].

However, broad access to palliative care for patients with COPD remains limited. Therefore, this study aimed to examine the current situation regarding palliative care in COPD through cases and explore ways to not only ensure a good quality of life but also uphold the dignity and value as human beings of patients with end-stage COPD.

MAIN TEXT

1. Case 1

A 69-year-old male patient with COPD, pulmonary hypertension, and right heart failure had been receiving long –term home oxygen therapy for 5 years. He had previously been hospitalized a year ago for respiratory failure due to hypercapnia and was discharged after improvement with mechanical ventilation. The patient was admitted because of worsening dyspnea that started a week prior. During an outpatient visit a month ago, the patient mentioned that he did not have much time left.

1) On the day of admission

Doctor: You have severe acute respiratory failure, and if this continues, there is a high probability that your condition will worsen. Therefore, mechanical ventilation through endotracheal intubation is necessary. Endotracheal intubation is essential for ensuring adequate oxygen supply and gaining time for treatment. However, since the endotracheal tube passes through the vocal cords and requires sedation, you will be unable to speak. Additionally, complications such as vocal cord edema and tracheal stenosis may occur. If prolonged intubation is necessary, a tracheostomy may be required.

Patient: Doctor, I don't want to suffer anymore. Please let me go comfortably. I don't want intubation or anything like last year. Please treat me well.

Caregiver: He is in a lot of pain. Just let him be comfortable.

2) Three days after admission

For 3 days, we used morphine and a face fan to relieve the dyspnea and provided oxygen therapy with a high-flow nasal cannula, ensuring adequate humidification. Despite the supportive treatment, the patient wanted to change the direction of the treatment. The patient expressed fear, describing it as feeling like drowning, and the guardians consented to the intubation.

Patient: I was treated until yesterday, but today it's really hard to breathe. I want intubation like last year.

Caregiver: I thought we could let him go comfortably, but since he wants it, please proceed with the intubation. Now that we've started, please do your best.

2. Case 2

A 74-year-old male patient had been receiving home oxygen therapy for 2.5 years for COPD. The patient had been living at home, and recently, the family caregiver mentioned that he struggled to wash his face and shampoo his hair due to shortness of breath. While sleeping, the patient suddenly experienced worsened dyspnea and decreased consciousness, leading to admission to the intensive care unit (ICU) after 30 min of cardiopulmonary resuscitation (CPR).

Caregiver: How did someone who was fine suddenly become like this? The attending physician didn't mention anything during the last outpatient visit... I'm just so overwhelmed.

Doctor: He was at a point where he couldn't even wash his hair or face; didn't he say anything specific?

Caregiver: We just thought it was something he dealt with every day. As long as it didn't get worse...

Doctor: Have you discussed what you would want to do if he got much worse? For example, performing CPR or using a ventilator?

Caregiver: No, we haven't. Neither we nor he could have imagined it would come to this... How can you talk about dying in front of someone?

DISCUSSION

From a practical perspective of what happened in Case 1, the opinions of the patient and family caregiver regarding the treatment changed continuously based on the patient's condition. This variability is reflected in the differences that arise during actual treatment implementation. Because the thoughts of the patient or family caregiver can change over time, making treatment decisions based on the patient's opinion at a single point in time may be problematic. Therefore, continuous consultations are necessary, and a therapeutic approach that must be discussed during this process is hospice and palliative care. We can imagine how the situation might have been different if hospice and palliative care approaches for end-stage COPD had been implemented for this patient before intubation [7-11]. If the physicians had provided a comprehensive explanation of the patient's condition to the patient and family caregiver promptly and if interventions regarding hospice and palliative care had been initiated, it is possible that they would have chosen to alleviate dyspnea through oral or injectable opioids, administer oxygen, and manage depression and anxiety, opting for treatment in the ward instead of invasive treat-

https://doi.org/10.14475/jhpc.2025.28.1.25

ment in the ICU [12-16].

While it is unclear what treatment options the patient or family caregiver would choose, an approach from the perspective of hospice and palliative care could potentially reduce the burden associated with the death process, which can not only be psychologically, emotionally, and physically painful after intubation and tracheostomy but also cause financial concerns.

In Case 2, it can be inferred from the questions and answers that the treatment for patients with end-stage COPD is limited to the symptom of dyspnea. The family caregiver did not recognize the anxiety and depression that the patient experienced due to his reliance on home oxygen therapy, inability to wash his face, and home confinement. Because they believed the patient was leading a normal life, they did not have the opportunity to prepare for death. Despite being an end-stage patient using home oxygen therapy, neither the patient nor the family caregiver had ever discussed death, hospice care, palliative care, or life-sustaining treatment. Often, family caregivers or healthcare providers do not know what values the patient holds or their perspectives regarding life-sustaining treatment. This reflects the limitations of adequately and intricately reflecting the patient's values, even among family members, and aligns with our culture's tendency to consider discussions about death as taboo. Moreover, it suggests the possibility that the patient may be left in a blind spot regarding information about their treatment, including hospice and palliative care.

In this case, the failure of the patient or family caregiver to prepare for death and obtain sufficient information about treatment may have been influenced by the indifference of the medical staff. This is supported by subsequent research indicating various responses from patients with COPD regarding intubation when faced with a high likelihood of ICU admission. Those with more severe symptoms showed more negative attitudes toward intubation, with 27~64% of patients willing to undergo intubation. Notably, 99% of patients with COPD expressed a desire to discuss intubation and mechanical ventilation with healthcare providers at the last moment. However, only 19% of them actually received counseling, and only 15% discussed supportive care therapies [17].

Traditionally, death has been regarded as an extremely personal event that must be concluded by a limited group of individuals surrounding the deceased. However, the increasing interest in social welfare, rise in hospital mortality rates, and reflections on the quality of life have transformed the nature of individual death from a private issue for the individual and their family into a communal issue that should concern healthcare professionals and society. Therefore, healthcare professionals are responsible for considering the quality of life and best interests of patients.

The in-hospital mortality rate for acute exacerbations of COPD accompanied by hypercapnia is 11%, with a 90-day mortality rate of 33% and a 1-year mortality rate reaching 43% [18]. Unfortunately, very few healthcare providers inform patients and family caregivers admitted for acute exacerbation of COPD with hypercapnia about these statistics or explain the approach to hospice and palliative care.

Furthermore, although patients with end-stage COPD experience dyspnea, anxiety, and depression, which are not experienced by patients with lung cancer, the application of hospice and palliative care for patients with end-stage COPD remains challenging in our country [19,20]. This difficulty arises not only from the perception that hospice and palliative care equate to the abandonment of treatment but also from the strong influence of Confucian culture in our society, which stigmatizes discussions about death, particularly when it comes to telling non-cancer end-stage patients directly [21,22]. However, failing to provide patients with proper information deprives them of the opportunity to make the best choices regarding their treatment.

The awareness of healthcare professionals regarding hospice and palliative care services that should be offered to patients with end-stage COPD is crucial. To provide patients and family caregivers who have primarily focused on the treatment of dyspnea with the opportunity to escape from anxiety and depression and to contemplate the best treatment while preparing for death, the proactive involvement of healthcare professionals is crucial.

Similar to patients with cancer, patients with end-stage COPD experience irreversible chronic progressive disease courses and experience an average of over seven physical, social, psychological, and functional issues in addition to physical symptoms that often lead to a decline in the quality of life. Therefore, there is no doubt that these patients require hospice and palliative care [23]. However, unlike patients with cancer, the main treatment for COPD, even in advanced stages, revolves around managing dyspnea, meaning that the treatment plan does not change significantly, whether early or late. Since the treatment often involves repeated management of exacerbations and remissions of dyspnea, other issues such as fatigue, anxiety, and quality of life degradation are easily neglected. Consequently, an approach incorporating hospice and palliative care, which can simultaneously address symptom management and social, spiritual, and psychological issues, should be initiated early.

In Korea, hospice and palliative care for patients with end-stage COPD is just beginning to take its first steps. Along with increased awareness among healthcare professionals, a thorough consideration of how to apply special circumstances for end-stage COPD, whether to utilize non-invasive or home mechanical ventilation for symptom control, or how to implement services such as pulmonary rehabilitation is warranted [24,25]. Moreover, a societal shift in perception is essential, allowing patients, healthcare providers, and families to engage in comprehensive discussions about the patient's condition, prognosis, treatment options, and death.

CONFLICT OF INTEREST

No potential conflict of interest was reported by the author.

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SUPPLEMENTARY MATERIALS

Supplementary materials can be found via https://doi.org/10.14475/jhpc.2025.28.1.25.

REFERENCES

1. Glare P. Predicting and communicating prognosis in palliative care. BMJ 2011;343:d5171.
2. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ 2005;330:1007-11.
3. Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. Age Ageing 2005;34:218-27.
4. Janssen DJA, Bajwah S, Boon MH, Coleman C, Currow DC, Devillers A, et al. European Respiratory Society clinical practice guideline: palliative care for people with COPD or interstitial lung disease. Eur Respir J 2023;62:2202014.
5. National Hospice and Palliative Care Organization. NHPCO's facts and figures: hospice care in America 2015. Alexandria, VA:National Hospice and Palliative Care Organization;2015.
6. Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomized controlled trial. Lancet Respir Med 2014;2:979-87.
7. Patel K, Janssen DJ, Curtis JR. Advance care planning in COPD. Respirology 2012;17:72-8.
8. Janssen DJ, Engelberg RA, Wouters EF, Curtis JR. Advance care planning for patients with COPD: past, present and future. Patient Educ Couns 2012;86:19-24.
9. Kreuter M, Herth FJ. Supportive and palliative care of advanced nonmalignant lung disease. Respiration 2011;82:307-16.
10. Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. Am J Respir Crit Care Med 2008;177:912-27.
11. Seamark DA, Seamark CJ, Halpin DM. Palliative care in chronic obstructive pulmonary disease: a review for clinicians. J R Soc Med 2007;100:225-33.
12. Barnes H, McDonald J, Smallwood N, Manser R. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane Database Syst Rev 2016;3:CD011008.
13. Smallwood N, Le B, Currow D, Irving L, Philip J. Management of refractory breathlessness with morphine in patients with chronic obstructive pulmonary disease. Intern Med J 2015;45:898-904.
14. Ekstrom M, Ahmadi Z, Bornefalk-Hermansson A, Abernethy A, Currow D. Oxygen for breathlessness in patients with chronic obstructive pulmonary disease who do not qualify for home oxygen therapy. Cochrane Database Syst Rev 2016;11:CD006429.
15. Yohannes AM, Alexopoulos GS. Depression and anxiety in patients with COPD. Eur Respir Rev 2014;23:345-9.
16. Blakemore A, Dickens C, Guthrie E, Bower P, Kontopantelis E, Afzal C, et al. Depression and anxiety predict health-related quality of life in chronic obstructive pulmonary disease: systematic review and meta-analysis. Int J Chron Obstruct Pulmon Dis 2014;9:501-12.
17. Heffner JE, Fahy B, Hilling L, Barbieri C. Attitudes regarding advance directives among patients in pulmonary rehabilitation. Am J Respir Crit

Care Med 1996;154:1735-40.
18. Connors AF Jr, Dawson NV, Thomas C, Harrell FE Jr, Desbiens N, Fulkerson WJ, et al. Outcomes following acute exacerbation of severe chronic obstructive lung disease. The SUPPORT investigators (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). Am J Respir Crit Care Med 1996;154:959-67.
19. Moens K, Higginson IJ, Harding R; EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. J Pain Symptom Manage 2014;48:660-77.
20. Au DH, Udris EM, Fihn SD, McDonell MB, Curtis JR. Differences in health care utilization at the end of life among patients with chronic obstructive pulmonary disease and patients with lung cancer. Arch Intern Med 2006;166:326-31.
21. Park SY, Phua J, Nishimura M, Deng Y, Kang Y, Tada K, et al. End-of-life care in ICUs in East Asia: a comparison among China, Korea, and Japan. Crit Care Med 2018;46:1114-24.
22. Shin DW, Lee JE, Cho B, Yoo SH, Kim S, Yoo JH. End-of-life communication in Korean older adults: with focus on advance care planning and advance directives. Geriatr Gerontol Int 2016;16:407-15.
23. Zhou HX, Ou XM, Tang YJ, Wang L, Feng YL. Advanced chronic obstructive pulmonary disease: innovative and integrated management approaches. Chin Med J (Engl) 2015;128:2952-9.
24. Mas A, Masip J. Noninvasive ventilation in acute respiratory failure. Int J Chron Obstruct Pulmon Dis 2014;9:837-52.
25. Janssen DJ, McCormick JR. Palliative care and pulmonary rehabilitation. Clin Chest Med 2014;35:411-21.