Tokai J Exp Clin Med., Vol. 47, No. 4, pp. 189-193, 2022

Palliative Care Intervention for End-of-life Patients with Non-cancerous Respiratory Diseases

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(Received March 7, 2022; Accepted August 26, 2022)

While palliative care for patients with cancer is actively performed, it is provided only occasionally for patients with chronic non-cancerous respiratory diseases. This is due to various factors, including the fact that palliative care is not covered by health insurance and the difficulty in determining end-of-life in these patients. This paper presents two case studies to highlight the significance of palliative care team intervention for patients in the terminal stage of chronic non-cancerous respiratory diseases. Palliative care is essential to support physical problems, such as dyspnea, as well as mental disorders, such as depression, and to provide nutrition therapy and rehabilitation. To achieve care at the appropriate time in accordance with the patient's wishes, it is essential for patients to understand and accept the progress and deterioration of their disease and prepare for the end of life at an earlier stage under multidisciplinary involvement (advance care planning).

Key words: palliative care, non-cancerous, respiratory, advance care planning

INTRODUCTION

Patients with chronic non-cancerous diseases experience a high symptom burden and worse quality of life than patients with cancer. However, they often do not receive access to palliative care support. For example, Mounsey reported that 40% of deaths in Australia were related to non-cancerous diseases, but only 14% of these patients accessed palliative care services [1].

During the period from May 2015 to December 2020, 116 patients with respiratory diseases received intervention from the palliative care team at our hospital, including 113 patients with malignant pulmonary diseases, 2 patients with interstitial pneumonia, and 1 patient with diffuse panbronchiolitis. In this paper, we present two case studies — one case of chronic obstructive pulmonary disease (COPD), where palliative care team intervention was not introduced but was considered desirable retrospectively, and a case of interstitial pneumonia, where palliative care team intervention seemed to have provided better end-of-life care. This study aims to determine the significance of palliative care team intervention in the terminal stage of chronic non-cancerous respiratory diseases.

This study was approved by the Institutional Review Board for Clinical Research, Tokai University (22J001). Informed consent was waived by the permission of the Institutional Review Board as this was a retrospective study that only utilized data from medical charts.

CASE 1

An 88-year-old-man was diagnosed with COPD at a hospital five years ago, and home oxygen therapy was initiated. A year ago, medical care was provided by a family doctor who initiated noninvasive positive pressure ventilation (NIPPV). The patient had been ill for several days, experienced a disturbance of consciousness, and was transferred to our hospital on an emergency basis.

Physical reports were as follows: Glasgow Coma Scale (GCS) 2-1-4, BP 166/84, P 82, body temperature 35.4°C, SpO_2 96% (O_2 8 L/minute per mask), and respiratory rate 30 times/minute. There were no audible breathing sounds on the left side of the chest, but a moist rale was heard on the right side.

Additionally, no prominent abnormal physical results were found. High $PaCO_2$ of 90 mmHg and impaired consciousness, but no apparent head disease on the image, suggested that CO_2 narcosis was the cause of impaired consciousness. Radiographic imaging on admission revealed left pneumothorax (Fig. 1a) and pulmonary emphysema (Fig. 1b). Lung expansion was good after the drainage of the left pneumothorax. NIPPV was performed again; $PaCO_2$ improved up to the 60 mmHg level, but the consciousness level only increased slightly to GCS 3-2-5.

Both the patient and his family had limited understanding of his condition. The patient's level of consciousness was too low at the time of admission to confirm his end-of-life wishes. Therefore, we held a joint multidisciplinary conference with doctors in the

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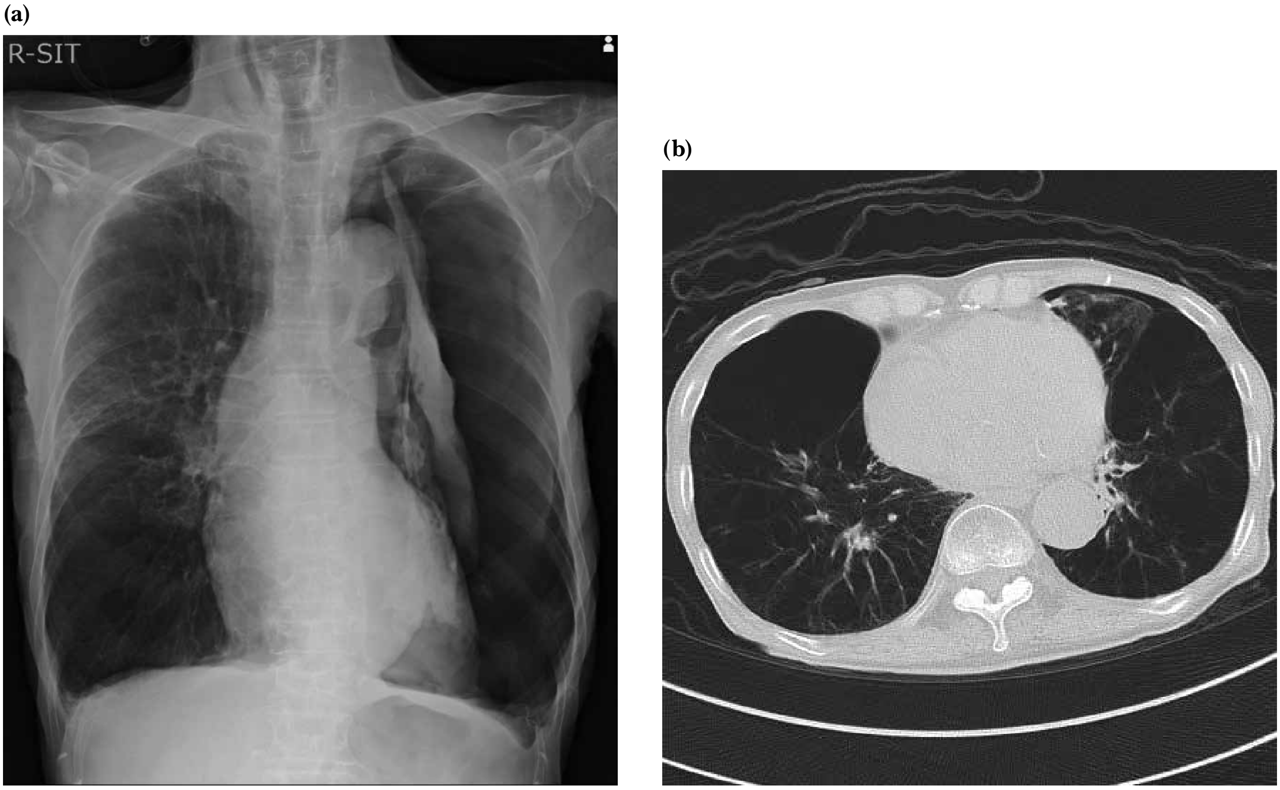

Fig. 1 Radiographic imaging of chest on admission of Case 1, revealing left pneumothorax (a) and pulmonary emphysema on the chest CT (b).

respiratory medicine department and nursing staff in the ward to determine the treatment plan after assessing the patient's wishes as presumed by the family. We decided to continue using NIPPV alone. Subsequently, the patient's condition gradually worsened, and he died 6 days after admission.

CASE 2

A 75-year-old man underwent hormone therapy for prostate cancer. He had been treated for rheumatoid arthritis at another hospital for five years with prednisolone (8 mg) and salazosulfapyridine (1000 mg).

As the patient's condition did not improve despite treatment for pneumonia at another hospital, he was transferred to our hospital. At admission, hypoxemia was observed with SpO_2 92% (O_2 2 L/minute), and physical findings showed dry rales on both sides of the lung field.

Antibacterial treatment was administered after admission to our hospital, but the patient did not respond. Therefore, we increased the steroid dose to temporarily improve the inflammatory response. However, the shadow of the lung field was exacerbated. Blood sampling revealed that the marker of interstitial pneumonia was KL-6 423 U/mL (not increased) and SP-D was 202 ng/mL (increased). Anti-CCP antibodies were 472 U/mL and RF 111 IU/mL, which are markers of rheumatoid arthritis. Imaging findings at the time of admission showed bilateral ground-glass and reticular shadows on radiography and chest CT (Fig. 2a and 2b). The symptoms worsened and gradual deterioration in oxygenation was observed. Therefore, we considered the possibility of acute exacerbation of rheumatoid arthritis-associated interstitial lung disease and administered steroid and cyclophosphamide pulse therapies. Despite this, oxygenation did not improve and dyspnea worsened. Therefore, we increased oxygen administration via nasal high flow (NHF). We administered intravenous morphine hydrochloride (10 mg/day) to relieve dyspnea. Oxygenation improved due to the maintenance of prednisolone and tacrolimus, but dyspnea persisted, and suicidal ideation appeared. Therefore, intervention by the palliative care team was requested.

The patient had been administered morphine hydrochloride 60 mg/day intravenously prior to the intervention. He had stated that he wanted to die quickly and comfortably and was depressed due to the pain and breathing difficulties. Despite the use of high-dose morphine hydrochloride and improved oxygenation, tachypnea was observed during awakening than sleeping. Additionally, labored breathing was observed. Although the patient admitted to suicidal ideation, it was not urgent and was thought to be due to mental and physical weakness due to the illness. Furthermore, we found that anorexia appeared, and continued, after starting morphine administration. Morphine did not affect dyspnea but exacerbated anorexia, and therefore, the dose was reduced and discontinued. However, the patient's anxiety and associated dyspnea persisted after opioid discontinuation. Hence, a psychiatrist and psychologist from the palliative care team treated the patient's spiritual pain, and reduced the anxiety and associated dyspnea using morphine 10 mg/day. Furthermore, despite continued high-dose steroids, anxiety and hopelessness were reduced by the intervention of the palliative care team. Based on these findings, we inferred that, in this case, spiritual pain was the cause of anxiety and associated dyspnea rather than the psychiatric symptoms that are side effects of

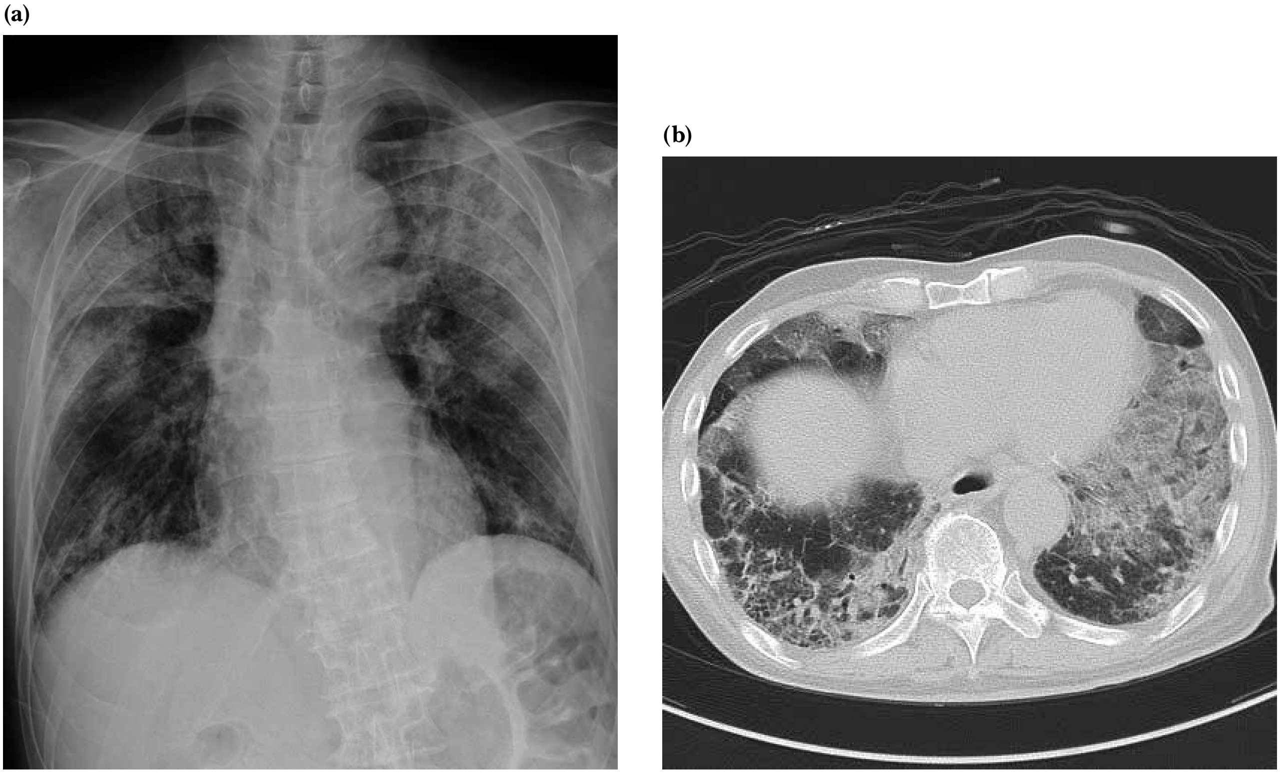

Fig. 2 Radiographic imaging of chest on admission of Case 2, showing bilateral ground-glass and reticular shadows.

opioid and steroid medications.

The patient died approximately one month later due to aspiration-led re-exacerbation of interstitial pneumonia.

DISCUSSION

In 2002, the World Health Organization (WHO) defined palliative care as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. However, there is often a lack of access to palliative care. Despite its effectiveness, early palliative care for patients with end-stage pulmonary diseases remains inadequate [2].

The course of chronic non-cancerous diseases is longer than that of malignant diseases. Since the subjective symptoms are mild at the initial stage, it is difficult to grasp the worsening or terminal stage of the condition. Consequently, it is more likely that patients with chronic non-cancerous diseases and their families will find it harder to understand and accept the worsening of the condition or being at the terminal stage, compared with patients with malignant diseases. In addition, due to the unpredictability of the prognosis, there is often a lack of explanation from medical staff about end-of-life at an appropriate time. Consequently, advance care planning (ACP) for the patient is often not discussed appropriately. Patients may not be able to spend their end-of-life period according to their own will because of their reduced decision-making capacity during this period. Palliative care for patients with chronic non-cancerous respiratory diseases often involves inadequate interventions in terms of preparing them physically, socially, and mentally for end-of-life. This is due to poor prognosis prediction and end-of-life awareness among patients and healthcare professionals. ACP is important but is not limited to improving the patient-physician relationship, respecting patient preferences, reducing family burden, and not rushing end-of-life discussions. However, several studies have described many barriers to addressing ACP between COPD patients and physicians or patients and their families, such as patient and family awareness, communication breakdowns, and uncertainty surrounding COPD prognosis [3, 4]. An umbrella review with implications for evidence-based practice demonstrated that the main barriers for professionals were lack of knowledge and skills to implement ACP, a certain fear of starting conversations about ACP, and a lack of time for discussions; for patients and their family members, these barriers included fear of discussing their loved one's end of life, lack of ability to perform ACP, and lack of knowledge about the person responsible for initiating conversations about ACP [5].

In a single-center study in Japan, 25% of COPD patients complained of respiratory symptoms such as dyspnea, but only 6% used opioids; 18% made spiritual complaints and 16% expressed their intentions after receiving explanations about their pathology and invasive treatments. Of the explanations given to families on the premise of death, 76% were given within eight days of the patient's death [6]. Another study examining palliative medicine at the end-of-life in patients with pulmonary fibrosis/interstitial pneumonia indicated that 97% of the patients experienced dyspnea in the three days before death. However, for drainage and antibacterial drugs, steroid interventions were used for 8%, 67%, and 84% of patients, respectively, while opioids were used for 13%. At the end of life, 10% of the patients expressed intention. Additionally, 24% of the respondents provided explanations to their families regarding what to do at the time of death and 1–2 days before death, 29% provided explanations for 3–4 days before death, and 22% for 5–8 days before death [7].

Traditionally, palliative care has been performed for patients with cancer; it has occasionally also been performed for patients with chronic non-cancerous diseases. A survey conducted on the current status of palliative care for patients with chronic non-cancerous diseases, targeting representatives of the Japanese Society of Palliative Medicine, included care for respiratory, cardiovascular, and neurological disorders. Although 87% of representatives recognized the need for palliative care for their illness, only 36% actually underwent the care, whereas 80% reported a lack of confidence in palliative care for non-cancerous conditions [8]. Palliative care interventions for non-cancerous respiratory diseases are also insufficient in other countries. In a population-based study in Belgium, Baernaert *et al.* reported that patients with COPD (20%) were far less often referred to palliative care services than those with cancer (60%) [9]. Furthermore, in a cohort study in the United Kingdom, Bloom *et al.* reported that only 16.7% of deceased COPD patients without lung cancer received palliative care support compared with 56.5% of deceased patients with cancer [10]. Partridge *et al.* reported that, in England, Wales, and Northern Ireland, only 21.5% of respiratory physicians developed formal policies and procedures in their departments for patients with chronic respiratory diseases near the end of life, and 97.5% of these were developed with the cooperation of colleagues who were specialists in palliative care [11].

In contrast, Abernethy and Johnson *et al.* reported that oral morphine and codeine administration improved shortness of breath scores assessed by the visual analog scale (VAS) in patients with COPD [12, 13]. Takeyasu *et al.* reported that among 17 of 22 patients with interstitial pneumonia in Japan, intravenous morphine administration in acute exacerbations resulted in moderate or greater improvement in dyspnea [14].

Multidisciplinary involvement including rehabilitation is important. Isselt *et al.* reported the effectiveness of implementing a program that included rehabilitation and palliative care for patients with severe COPD [15]. Higginson *et al.* reported that patients experiencing dyspnea were diagnosed with chronic non-cancerous respiratory diseases including COPD (54%) and interstitial pneumonia (18%), as well as cancer (20%) and heart failure (5%). Patients who received multidisciplinary services that integrated respiratory physiotherapy, occupational therapy, and palliative care, in addition to regular maintenance, showed significantly better results than those in the control group. Furthermore, the results also revealed a significantly higher survival rate, especially among patients without cancer [16]. This suggests that end-of-life palliative care interventions for patients with chronic non-cancerous respiratory illnesses are essential. Through palliative care, it is possible to deal with physical symptoms, such as dyspnea, and mental health issues, such as depressive symptoms. Additionally, palliative care promotes patients' and their families' understanding of the medical condition and acceptance of feelings for progression/deterioration. Nutritional and rehabilitation therapies (respiratory muscles, physical fitness maintenance, and sputum drainage) are also necessary. We believe it is important for patients, and their families, to understand and accept their current medical condition and future prospects, and examine and prepare for their desired end-of-life environment. Therefore, medical professionals should introduce palliative care, including ACP, with the cooperation of multiple occupations from an early stage, alongside proper understanding and treatment of medical conditions centered on patients and their families.

In Case 1 of the present study, it was difficult to ascertain the patient's end-of-life wishes when he was admitted to our hospital. Originally, he was in the terminal stage of COPD; however, he and his family had little understanding of his medical condition. During home management, until admission, when the level of consciousness declined, the patient's wishes for end-of-life care could not be ascertained. Therefore, the end-of-life care plan was based on the patient's wishes as presumed by his family, and discussed at a multidisciplinary conference. As a result, it was decided that invasive medical treatment (re-drainage at the time of pneumothorax recurrence, ventilator by tracheal intubation, and chest compression) would not be performed. If the palliative care team had intervened early and performed ACP, the patient could have received end-of-life care based on his wishes. This highlights the importance of early palliative care team intervention and ACP.

In Case 2 of the present study, the patient experienced dyspnea and spiritual pain. However, with the palliative care team intervention, that included psychologists and psychiatrists, the patient's symptoms reduced with less morphine than before the intervention. Palliative care, including both physical and psychological care, provided at an early stage enabled the patient to have a relatively good end-of-life. This also highlights the importance of palliative care team intervention and ACP at an early stage.

Patients with chronic non-cancerous respiratory diseases experience physical distress, such as breathlessness, fatigue, and reduced ability to perform daily living activities. They also experience social pain, such as restrictions on social activities due to the introduction of home oxygen. Mental distress, such as depression, also increases. Such distress at the end of life requires early intervention. Therefore, ACP is as important in non-cancer patients as in cancer patients. However, providing palliative care to patients with non-cancerous diseases is often more difficult than providing it to patients with cancer. In Japanese hospitals, active end-of-life palliative care intervention for patients with chronic non-cancerous respiratory diseases, unlike that for those with end-stage heart failure and AIDS, is challenging due to the disapproval of medical fees.

In Japan, the "Non-malignant Respiratory Disease Palliative Care Statement" was first published in 2021 by the Japanese Respiratory Society and the Japanese Society for Respiratory Care and Rehabilitation. The importance of palliative care for non-cancerous respiratory diseases should be reaffirmed and promoted nationwide.

At our hospital, the introduction of palliative care for chronic non-cancerous respiratory diseases remains inadequate. In the future, as a palliative care team, we will need to create a system that allows us to actively intervene with cancer patients and patients with chronic non-cancerous respiratory diseases.

CONCLUSION

Palliative care for patients with chronic non-cancerous respiratory illnesses is needed to provide support for physical problems, such as dyspnea, and mental disorders, such as depression. It is necessary to understand the medical condition, accept the progression and aggravation of the disease, and build an end-of-life system desired by the patient. Therefore, multidisciplinary involvement is essential and should be performed at an appropriate time.

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