

While I breathe, I hope. *Principles of palliative care in chronic breathlessness and advanced lung diseases*

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**memo - Magazine of European
Medical Oncology**

An International Journal for Oncology
and Haematology Professionals

ISSN 1865-5041

memo

DOI 10.1007/s12254-019-00556-1



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While I breathe, I hope. Principles of palliative care in chronic breathlessness and advanced lung diseases

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Received: 13 October 2019 / Accepted: 7 December 2019
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Summary The ancient Latin quote *Dum spiro, spero* from Cicero means *While I breathe, I hope*. This article outlines five clinically relevant principles for pulmonary palliative care to treat chronic breathlessness in advanced lung diseases: (1) be aware of the finality of life, (2) palliative care does not mean “doing nothing”, (3) consider interdisciplinary and multidisciplinary therapeutic concepts, (4) conduct future talks and (5) use opioids for refractory breathlessness and think of treatable causes of respiratory distress.

Keywords Dyspnea · Neoplasms · Lung diseases · Palliative care · Respiration

The ancient Latin quote *Dum spiro, spero* from Cicero means *While I breathe, I hope*.

The symptom shortness of breath is the result of interactions between different physiological, psychological, social and environmental factors which in turn lead to further physiological as well as behavioral reactions [1]. It has recently been renamed as a syndrome called “chronic breathlessness” [2]. Incurable diseases in a palliative setting can lead to the syndrome of chronic breathlessness, which is characterized by chronic respiratory distress at rest or under minimal exercise despite optimal therapy of the underlying causes [3]. Palliative care and palliation comprise an active form of therapy for patients who suffer from incurable, mostly advanced illnesses. For a long period, palliative care was delivered primarily to patients suffering from oncological diseases, as

these patients were recognized as needing symptom management and attention regarding quality of life. However, the symptom burden of patients with severe chronic obstructive pulmonary disease (COPD) is comparable to that of patients suffering from lung cancer, with a significantly longer duration in survival (survival in COPD patients: median 589 days, survival in patients suffering from lung cancer: median 107 days) [4]. Therefore, non-oncological patients suffering from chronic lung diseases are likely to benefit and therefore also deserve pulmonary palliative care.

Five clinically relevant principles for pulmonary palliative care are outlined below.

Be aware of the finality of life

Since medicine is primarily focused on healing, the finite nature of life is particularly difficult to understand for doctors and medical teams, but also for patients and their caregivers. In the face of an incurable illness, a prerequisite for patients to receive palliative care is to focus on the personal wishes of the patients leaving the maximization of therapeutic options as the secondary focus in the background.

Providing good symptom control, enhancing quality of life, anticipatory planning (advance care planning) as well as involving caregivers are cornerstones of palliative care. Palliative care takes into account the principle of “*high person, less technology*” by palliative care pioneer Cicely Saunders. An openness to discuss topics relating to the end of life, death and dying should be regarded as a core competence for all those working in a medical profession.

Palliative care does not mean “doing nothing”

Palliative care is not limited to end of life care, but should rather be integrated into patient care at an

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Table 1 Palliative care/hospice criteria [25]

Criteria for hospice eligibility of patients with advanced lung disease
Patients will be considered to be in the terminal stage of pulmonary disease (life expectancy of six months or less) if they meet the following criteria. The criteria refer to patients with various forms of advanced pulmonary disease who eventually follow a final common pathway for end-stage pulmonary disease. (Criteria 1 and 2 should be present. Criteria 3, 4, and 5 will lend supporting documentation):
1. Severe chronic lung disease as documented by both a and b:
(a) Disabling dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity (e.g., bed-to-chair existence), fatigue, and cough. (Documentation of FEV ₁ , after bronchodilator, less than 30% of predicted is objective evidence for disabling dyspnea, but is not necessary to obtain.)
(b) Progression of end-stage pulmonary disease, as evidenced by increasing visits to the emergency department or hospitalizations for pulmonary infections and/or respiratory failure or increasing physician home visits before initial certification. (Documentation of serial decrease of FEV ₁ > 40 ml/year is objective evidence for disease progression, but is not necessary to obtain.)
2. Hypoxemia at rest on ambient air, as evidenced by Po ₂ less than or equal to 55 mm Hg; or oxygen saturation less than or equal to 88% on supplemental oxygen determined either by arterial blood gases or oxygen saturation monitors; OR hypercapnia, as evidenced by Pco ₂ ≥ 50 mm Hg. These values may be obtained from recent (within three months) hospital records
3. Right heart failure secondary to pulmonary disease (cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy)
4. Unintentional progressive weight loss of greater than 10% of body weight over the preceding 6 months
5. Resting tachycardia >100/min
FEV ₁ forced expiratory volume, Po ₂ partial pressure of oxygen, Pco ₂ partial pressure of carbon dioxide

early stage of an incurable disease. The results of a randomized study published in the *New England Journal of Medicine* in the year 2010 revealed that the life of patients with stage IV lung cancer was prolonged by three months compared to standard oncology treatment by offering early palliative care after initial diagnosis [5]. The palliative care intervention consisted of caring for the patients at least once monthly by a palliative team and assessing physical and psychosocial impairments. Furthermore, the study results revealed that psychological complaints such as anxiety or depression were significantly lower in the group of patients receiving palliative care. Hence, it can be concluded that palliative care does not lead to a loss of hope. Palliation is the action management of all symptoms (physiological and psychological).

Palliative care promotes future care planning, which means patients and their families/loved ones have the opportunity to discuss and record their preferences, wishes and desires in case a situation arises when they cannot speak for themselves. Evidence tells us that patients and their caregivers appreciate being actively informed about the option of palliative care [6, 7].

Consider interdisciplinary and multidisciplinary therapeutic concepts

No (wo)man is an island. A recent study described a *holistic approach* in the form of breathing training, relaxation techniques and psychological support as a goal-oriented measure in dealing with chronic respiratory distress [8]. Respiratory therapists and respiratory outpatient clinics, as already established in the UK, are a valuable part of a pneumonology team as well as a palliative care team.

Dyspnea is what the patients says it is [9]. While respiration rate, oxygen saturation, and lung function do not provide information about the individual experience of burden, subjective assessment in the form

of sensory experience, emotional stress and daily restrictions due to respiratory distress is recommended [10].

In general, physical, mental and social care, taking into account cultural as well as spiritual aspects, best describe the so-called *pallium*, which is synonymous with a cloak in which the patients can slip in and feel protected. In regard to advanced lung diseases, interdisciplinary cooperation benefits the patients in terms of comprehensive therapeutic concepts.

Conduct future talks!

Palliation and curation should not be considered as two mutually exclusive worldviews. The curative-restorative approach is usually geared to short-term goals, while the palliative approach focuses more on predictive planning [11]. Often, both approaches interlock and within the medical profession, one should never stop scrutinizing the facts. Even in a palliative situation, longevity may be gained by considering comorbidities, by cooperating interdisciplinarily, and importantly by giving patients the feeling of still being present when a palliative care approach—which may not be one's own field of expertise—has been initiated. Conversations about the end of life usually take place about a month before death of the patients and are mostly not conducted by the primary treating physician [12].

Patients with incurable lung diseases lack understanding of their condition and knowledge about the dynamics of COPD or similar fatal diseases and the possibility of dying from this disease, as well as patient education and reassurance of appropriate symptom management (e.g. to prevent sensation of suffocation) are well-accepted measures to help these patients [13]. Eligibility criteria for palliative care units and hospices can be found in Table 1. The article *Emotions in the room: common emotional reactions to discussions of poor prognosis and tools to address them*

by Derry et al. provides a good overview of how to deal with patients' emotional responses to a poor prognosis [14].

Furthermore, the *Surprise Question* can serve as a helpful tool in clinical decision-making. The results of a study among general practitioners revealed that if the question, "Would you be surprised if the patient dies within the next year?" was answered with "No", the predictive value was very high and patients with palliative care needs could be well identified [15].

Use opioids for refractory breathlessness and think of treatable causes of respiratory distress

Opioids serve as a grade 1 recommendation for symptom control concerning respiratory distress in the palliation of advanced lung diseases when symptom control by using bronchodilators, diuretics, corticosteroids and other soothing measures (e.g., long-term oxygen therapy, bronchial stenting, blood transfusions, thoracocentesis, treatment of pulmonary embolism, antimicrobial therapy for pneumonia, treatment of heart failure, radiotherapy) were insufficient [16]. In COPD and pulmonary fibrosis, opioids reduce respiratory distress [17, 18]. Opioids affect the limbic system, which leads to calmer and deeper breathing. Opioids are not used with the primary indication to sedate patients. All opioid use must be monitored for signs of opioid toxicity: myoclonus, neurological excitation, agitation and delirium.

If sedation is required to alleviate refractory symptoms, midazolam is one option which can be used in a palliative care setting [19, 20]. Palliative sedation has been shown not to shorten life and should be regarded for a form of symptom control for severe symptoms. It is not a treatment to hasten death nor as a kind of *slow euthanasia* [21]. Benzodiazepines are not intended as a routine medication for breathlessness but serve as a second- or third-line therapy, benefitting patients through their anxiolytic actions [22].

Oxygen therapy through a mask or a nasal cannula is indicated only in case of proven hypoxemia. The use of a hand-held fan can be recommended to patients without hypoxemia, as trigeminal stimulation has shown to reduce symptom burden in non-hypoxic patients [23, 24].

Listen to your patients, they will tell you what they need (Cicely Saunders)! In summary, acquiring palliative care skills can lead to better management of those with serious illnesses and can help patients cope with their illnesses better.

Funding Open access funding provided by Medical University of Vienna.

Conflict of interest E.K. Masel declares that she has no competing interests.

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