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Educational aims

- To explain the basic domains of palliative care applicable to chronic respiratory diseases.
- To review palliative care interventions for patients with chronic respiratory diseases.
- To outline a checklist for clinicians to use in practice, based on the domains of palliative care.
- To propose recommendations for clinical management of patients receiving palliative care for chronic respiratory diseases.



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The potential of palliative care for patients with respiratory diseases

Based on the demonstrated effectiveness of palliative care in the alleviation of symptoms and enhancement of life quality, it is important to incorporate palliative care early in the respiratory disease trajectory. Quality palliative care addresses eight domains that are all patient and family centred. Palliative care interventions in respiratory conditions include management of symptoms such as dyspnoea, cough, haemoptysis, sputum production, fatigue and respiratory secretion management, especially as the end-of-life nears. A practical checklist of activities based on the domains of palliative care can assist clinicians to integrate palliative care into their practice. Clinical management of patients receiving palliative care requires consideration of human factors and related organisational characteristics that involve cultural, educational and motivational aspects of the patient/family and clinicians.

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Early palliative care can relieve suffering and provide support for people with respiratory diseases <http://ow.ly/z0Hd30jpsb4>

According to the World Health Organization (WHO), palliative care is defined as “an approach that improves the quality of life of patients and their families facing problems associated with [serious] life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [1].

Patients facing life-threatening illness often experience unnecessary and preventable suffering including extreme and prolonged pain and other symptoms, psychological distress and experience poor communication with clinicians, resulting in enormous strain on patients and caregivers [2, 3]. Unmet needs in the physical, psychosocial and spiritual domains are common [4]. As a result, the last few weeks and months of life may be additionally burdened with physical, emotional and spiritual suffering on the part of the patient and their loved ones. Early introduction of palliative

care could improve function and quality of life (QOL) for individuals with serious, life-limiting conditions, such as patients with respiratory diseases, throughout disease trajectories and across all healthcare settings [5].

In many areas of the world, “supportive care” is the preferred wording in describing this service rather than “palliative care”, as the connection between palliative care and hospice services was reported by patients and families to increase distress and decrease hope [6]. To focus this article on the goals of palliative care, we will consider “palliative care” interchangeable with “supportive care” as appropriate to health and disease care (table 1).

In 2017 MEIER and MORGAN [7], in describing their work at the Center to Advance Palliative Care, suggested a more comprehensive definition of palliative care as: “...specialized medical care for people with serious illnesses... focused on providing patients with relief from the symptoms, pain, and stress of a serious illness... to improve quality of life



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Table 1 *Palliative care goals*

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;
- [Can apply] early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those inquiries needed to better understand and manage distressing clinical complications.

Reproduced from [1] with permission.

for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment". This updated definition is consistent with the WHO definition of services focused on pain and symptom management by an interdisciplinary team, including psychosocial and spiritual care consistent with patient/family needs, values, preferences, culture and beliefs. There are multiple studies that have demonstrated the benefits of palliative care in terms of reduction of patient symptoms and enhancing patient QOL, resulting in high levels of patient and family satisfaction with care, and in reducing readmissions to hospital with related cost-benefits to healthcare systems. To more effectively improve QOL, reduce depressive symptoms, support

and help communication about end-of-life care preference, palliative care is best integrated in programmes or through consultations specific to the patient, family and disease, just as oncology care is personalised [8, 9].

Palliative care programmes, *i.e.* interdisciplinary care focused on relief of pain and other symptoms in support of best possible QOL for patients with serious illness and their families, or consultations with palliative care experts where such programmes are not available have both been shown to reduce symptoms, alleviate suffering, improve doctor-patient communication and satisfaction with care, improve family satisfaction, and enhance the efficiency and effectiveness of hospital services [8, 10]; they are also associated with hospital cost savings [11, 12]. Palliative care consultations for inpatients have successfully identified unrecognised symptoms and unmet problems [13, 14]; and have been associated with lower use of intensive care units (ICUs) [15], lower likelihood of dying in an ICU [8], lower costs of care [12] and improvement in care processes, including opioid prescribing and documenting patient goals for care [13, 16].

People often confuse palliative care and hospice care. Hospice care systems were designed to be used at the end of life. The hospice model of care, depending on the country, can limit admission to a hospice to those with a 6-month prognosis for life and in many systems requires the discontinuation of "curative" treatments [6]. Palliative care, by contrast, is recommended for all patients with serious symptoms, with initiation at the time the patient is first diagnosed and continued throughout the disease trajectory.

Multiple studies have demonstrated that transforming care for the population living with serious and life-threatening conditions requires a fundamental shift towards palliative care that is coordinated around a range of services and patient conditions. Palliative care teams have been a very effective component of inter-professional holistic care. Professional-level interactions may include advice or case conferencing, as well as support among clinicians about the case. Clinician-patient communication is significantly improved when palliative care professionals, who receive extensive training in compassion and communication, are part of the team. A palliative care consultation, usually with a palliative care physician or nurse practitioner, has also been demonstrated to improve symptom relief and enhance QOL in patients whose primary physician is of another specialty [17]. Palliative care, with appropriate coordination and monitoring of care, can assist in reducing anxiety and can empower patients and families by supporting their wishes throughout the illness trajectory, as well as during the dying process. A Cochrane database systematic review of palliative care found reliable evidence that home palliative care meets patients desire to die at home and lessens symptom burden, especially in patients with cancer [18]. Figure 1

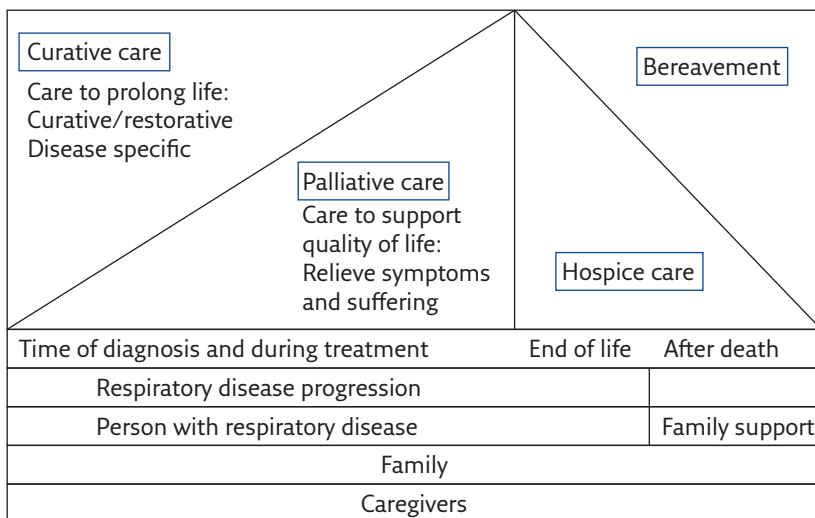


Figure 1 *Model of palliative care for respiratory disease. Adapted from [65].*

adapts a model of palliative care to patients with respiratory disease.

In developing palliative care systems, training programmes are essential. Palliative medicine is a medical subspecialty in Canada, UK, Ireland, Australia, New Zealand and the USA. As of 2014, 18 out of 53 countries in Europe reported certification in palliative medicine as a specialty or subspecialty, they were (in alphabetical order): Czech Republic, Denmark, Finland, France, Georgia, Germany, Hungary, Ireland, Israel, Italy, Latvia, Malta, Norway, Poland, Portugal, Romania, Slovakia, and the UK [19]. The trend for specialisation in this area is evident. These specialty trained providers are key to the palliative care interdisciplinary team of doctors, nurses, social workers, chaplains and other specialists. Palliative care specialist education includes how to comprehensively coordinate care with other clinicians and within

the team, manage symptoms, and help patients and families to cope with their stressors. Training programmes are critical to implementing quality palliative care.

The National Consensus Project for Quality Palliative Care [20] categorises quality palliative care within eight domains, all of which are patient and family centred. Table 2 lists brief descriptions of the eight domains.

Using palliative care that provides integrated healthcare for individuals with respiratory diseases has shown great potential to improve patient care and outcomes [21]. A palliative care model using interdisciplinary teams has demonstrated ability to improve care for patients with advanced lung disease through managing pain and other symptoms, facilitating interpersonal communication, supporting shared decision making, and coordinating care [22].

Table 2 Domains of palliative care as categorised by the National Consensus Project for Quality Palliative Care “Clinical Practice Guidelines”

Domain	Brief description
Structure and processes of care	The interdisciplinary team assessment is based on: patient/family goals of care; the diagnosis/prognosis; continuity across the levels of care that a patient needs (<i>e.g.</i> inpatient unit, home); and incorporating quality and safety.
Physical aspects of care	The assessment (validated tools) and multidimensional treatment of physical symptoms such as pain, dyspnoea, nausea/vomiting, fatigue, constipation, performance status, medical diagnoses and medications (add/wean/titrate). Specific policies for treatment include pharmacological, interventional, behavioural and complementary management.
Psychological and psychiatric aspects of care	A collaborative assessment process of psychological concerns and psychiatric diagnoses that includes patient–family communication and treatment options. Specific concerns assessed include: anxiety, depression, delirium and cognitive impairment; stress, anticipatory grief and coping strategies; pharmacological and non-pharmacological treatment; and patient/family grief/bereavement programmes of care.
Social aspects of care	Interdisciplinary collaboration with patients and family/friends focused on communication, interaction, and support to identify patient and family strengths and incorporate the professional social worker. Caregiver crisis is defined with a goal of prevention.
Spiritual, religious, and existential aspects of care	Assessment of spirituality with access to staff collaboration to address spiritual concerns throughout the disease trajectory. This domain promotes exploration of hopes, fears and forgiveness, and is designed to promote practices for comfort and relief.
Cultural aspects of care	Cultural competence is defined for the interdisciplinary team, with a view of culture as a source of strength and resilience for patients and families. Linguistic competence stresses plain language, literacy and linguistically appropriate service delivery.
Care of the patient at the end of life	Communication and documentation of signs and symptoms of the process of dying are emphasised. Management of pain and other symptoms are considered critical to alleviate suffering. Bereavement support begins with recognition and communication to patient/family about prognosis (<i>e.g.</i> hours to days) and support for anticipatory grieving. Social, spiritual and cultural care is critical.
Ethical and legal aspects of care	The focus in this domain is on advance care planning with ongoing discussion of goals of care, acknowledgement of the complexity of ethical issues along with the importance of seeking help from ethics councils, and acknowledgement of the complexities of legal and regulatory issues, with access to legal counsel supported.

Information from [20].

Respiratory conditions and palliative care

Respiratory conditions that may benefit from palliative care include, but are not limited to: lung cancer, COPD, cystic fibrosis, and pulmonary hypertension. Palliative care in these respiratory conditions often includes symptom management and support of patients with dyspnoea, cough, haemoptysis, sputum production, fatigue, and respiratory secretion management, especially as the end-of-life nears. Helping people manage their symptoms and improving a patient's ability to live with serious respiratory conditions are international concerns [19]. Clinical practice guidelines are important in palliative care planning, which includes both disease-focused and palliative treatments [20]. Comparison examples of disease-focused and palliative treatments in respiratory diseases are presented in table 3.

Palliative care and lung cancer

Lung cancer is the second most commonly diagnosed cancer; and globally, lung cancer is the most common cause of death from cancer, with 1.38 million deaths recorded in 2008 (18.2% of the total of all cancer deaths according to the American Lung Association lung cancer fact sheet and the GLOBOCAN 2008 report) [23, 24]. Likewise, the financial burden of lung cancer is high. National expenditures for lung cancer were estimated at USD 13.4 billion for 2015 in the USA and EUR 18.8 billion in the European Union, making lung cancer the most costly of all cancers worldwide [25, 26]. Management of patients with lung cancer is an increasingly complex issue as patients live longer with growing symptom burdens.

The majority of patients with lung cancer are still diagnosed at a late stage and receive standard, active cancer therapies including radiation, surgery and chemotherapies. Lung cancer continues to have a poor prognosis. Progressive cancer treatment may cause persistent residual side-effects and result

in advanced lung cancer patients suffering from numerous symptoms, especially fatigue, appetite loss, dyspnoea, cough, pain and depression [27, 28]. High levels of symptom clusters and distress decrease their ability to manage symptoms, exacerbate disease progression and lower their hope, and as a result functional ability and health-related QOL are extremely low [29, 30]. Hope and freedom from suffering are important for coping with lung cancer; lack of hope has increased cancer symptoms and psychological distress among lung cancer patients [29]. In addition to adverse reactions to treatment, advanced lung cancer patients undergo the burden of the natural course of the disease as well as the uncertainty of survival [30]. These escalating symptom-reaction consequences require more healthcare services, which in turn results in negative life consequences not only for the patients but also their family/caregivers [18, 31]. Optimal management with palliative care could improve symptoms, anxiety and disease morbidity, as well as reduce costs among patients with lung cancer.

Palliative care and COPD

The prevalence of COPD is increasing worldwide [32]. Its incurable nature and unpredictable course, with resulting intense symptom distress and poor QOL, have led to recognition of the potential of palliative care to mitigate the challenges patients and families face [33]. COPD, including emphysema and bronchitis, is a disease of airflow obstruction that makes breathing and activity difficult. Smoking, air pollution, genetic defects and respiratory infections are all aspects of the increase in cases of COPD worldwide. The WHO COPD fact sheet reported that 65 million people have moderate-to-severe COPD and 5% of all deaths worldwide are caused by the disease [32]. Half of adults who have difficulty functioning physically have COPD without being diagnosed [34].

A retrospective study of 339 British patients who died of COPD, found that 41% either left the house less than once per month or never left, and 47% were hospitalised at least twice during the final year

Table 3 Comparison of disease-focused and palliative treatments in respiratory diseases

Condition	Disease-focused treatment	Palliative treatment
Lung cancer	Surgery/radiation/chemotherapy	Treatment of side-effects from medical treatments, such as management of fatigue, nausea, decreased appetite and dyspnoea
Chronic obstructive pulmonary disease (COPD)	Bronchodilators (oral/inhaled)/oxygen/pulmonary rehabilitation	Counselling and medications to reduce anxiety and dyspnoea; moving air (fan) to reduce dyspnoea perception
Cystic fibrosis (CF)	Antibiotics/enzymes/percussive therapy/lung transplant	Teaching mastery skills to manage dyspnoea, opioids to control intractable coughing
Pulmonary arterial hypertension (PAH)	Antibiotics for infection/targeted medications/oxygen	Discussions of disease trajectory/treatment options/advanced care planning

of life; 67% died in the hospital and only 63% knew that they could die from COPD [35]. Others have also confirmed that patients with COPD are often unaware of the progressive course of their disease and the possibility they could die from COPD [36].

Symptom burden has been described as greater than lung cancer [37] with dyspnoea the most reported symptom. Disease-focused care in COPD involves multifaceted assessments to monitor the disease and symptoms, reduce risk factors of smoking and air pollution exposure, slow disease progression, cope with exacerbations, and address the psychosocial needs of patients and caregivers. Disease-focused treatment is for symptom management, improving functional abilities, and ongoing surveillance to prevent exacerbations [38].

The proportion of hospitalised COPD patients with documented unmet palliative care needs was almost twice as great as other hospitalised patients, yet only 10% of those had physicians who recognised their need for palliative care [39]. The issue of inadequate palliative care in COPD is one example of healthcare inequality that can be improved by addressing the barriers of prognostic uncertainty, low provider skill in palliative care discussions, fear of opioid treatment for respiratory disease symptoms, fear of losing hope, and implicit bias against patients who smoke or have smoked [40].

Palliative care along with disease-focused evidence-based care with ongoing patient education and support are needed [41]. Studies have documented that palliative care in COPD is more effective when offered earlier in the trajectory, rather than waiting for referrals at the end of life [40, 42]. Palliative care, incorporating advanced care planning, can improve life quality by proactive, collaborative disease treatment, with appropriate use of opioids to support care and comfort together [22, 34, 43].

Palliative care and CF

CF is a frightening genetic disease affecting primarily the lungs and digestive system, due to defective proteins that result in unusually copious, sticky mucus obstructing the lungs leading to infections. Today, three-quarters of CF cases are diagnosed by the age of 2 years and a majority of those living with CF are 18 years or older. Life expectancy of children with CF was so low in the middle of the last century that most died before attending school. Remarkable progress has led to intense improvements in length and QOL for patients with CF, including options for lung transplants and gene therapies, such that those born in the 21st century are expected to live into middle-age [44]. As a result this chronic, progressive disease presents complex and ongoing challenges in management, and research suggests that palliative care consultation early in the process could be an important component of treatment [45].

Children and adults with CF today have more therapy options than they have ever had before:

medications to clear the mucus from airways and reduce inflammation; aerosolised antibiotics; and, recently, breakthrough genetic therapy to address the underlying cause of CF. Palliative care helps patients with CF to cope with symptoms and treatments, psychologically adjust to the trajectory of the disease, consider the impact of lung transplantation, and plan for the end of life. KARLEKAR *et al.* [46] found that, although few patients with CF had completed an advanced directive, 90% were willing to have the discussion and desired their clinicians help in decision-making. A palliative care consultation could have met their needs by integrating team-based care and decision support to assist in improving coping skills, pain management, treatment adherence, and advanced care planning into their disease-focused care [45].

Palliative care and pulmonary hypertension

The WHO divides pulmonary hypertension (PH) into five groups based on the cause of the condition. In all groups, the average pressure in the pulmonary arteries is higher than 25 mmHg at rest or 30 mmHg during physical activity. Due to the nonspecific nature of symptoms, PH is most frequently diagnosed when patients are in the advanced stages of the disease [47]. Currently, there is no cure for PH and treatment is solely aimed at improving symptoms and exercise tolerance, long-term outcomes and QOL, as well as slowing the rate of deterioration [48]. Pulmonary arterial hypertension (PAH) is a rare (estimated prevalence of 15–50 cases per million) subset group of PH, characterised by progressive pulmonary vascular resistance, leading to right heart failure and death. Disease management in PAH is complex involving a range of treatment options including prevention and prompt treatment of chest infections, as well as supportive oxygen therapy and medication [49]. As such, palliative care assessment supporting lifestyle changes, medicine to relieve treatment side-effects and suffering should be considered. Palliative care can be concomitant with PH and PAH therapies to treat symptoms. PAH diagnosis is progressive and non-curable, and therapies and symptoms are life-limiting [50]. When current PH/PAH therapy includes undesirable side-effects palliative care referral should be implemented if it has not yet been done. Palliative care is an option to consider when PH/PAH patients present with challenging psychological, social or spiritual symptom management issues, when the patient is experiencing decreased function, or it is not possible to provide more intense therapy [47]. If emergency department visits/admissions within 12 months increase with the worsening symptoms, palliative care could support family coping/advanced care planning and link the patient and family to additional resources such as pastoral counselling or social

workers. Nine out of 10 patients and families are willing to discuss advanced directives [46]. Research by PROVENCHER and GRANTON [51] studying patients with PAH documented that a “supervised rehabilitation program, psychosocial support, and referral to palliative care [can] lead to improvements in exercise capacity and quality of life”.

Palliative care symptom management for patients with respiratory diseases

The use of palliative care in advanced respiratory diseases such as lung cancer, COPD, CF and pulmonary hypertension is complex and has been offered in multiple ways including palliative care consultations, direct palliative care team management and specialised centres for palliative care [52]. The desired outcomes of palliative interventions are to enable early detection of disease exacerbations, provide timely intervention for early symptom management, decrease patient and family/caregiver anxiety, reduce unscheduled visits to the emergency room, prevent hospitalisations, and support advanced care planning to avoid suffering, especially at the end of life. Common symptoms in respiratory diseases are dyspnoea, cachexia, fatigue, haemoptysis, cough (with and without sputum), physical pain, and psychosocial discomfort. A brief description of actions for symptom management is provided here; however, an in-depth discussion of the management of these symptoms is beyond the scope of this article and the reader is referred to the ERS Monograph on Palliative Care in Respiratory Disease [53].

Dyspnoea has many causes and management focuses on the cause; relief of obstructions or pleural effusions may be helpful in addition to medications, supplemental oxygen or other indicated treatments. Assessment and management of dyspnoea should include a plan for “dyspnoea crisis”, *i.e.* the “sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-threatening illness and overwhelms the patient and caregivers’ ability to achieve symptom relief” [54]. The word COMFORT can be used to plan for a dyspnoea crisis with these customisable steps: Call for help; Observe and assess for causes; Medicate as per clinician’s plan (*e.g.* opioid use); Fan to face may help; Oxygen as prescribed; Reassure and help relax; and Timing record of what works and when to use in future.

Cachexia including symptoms of appetite loss, nausea and changes in taste can be debilitating. Approaches can include a nutrition consultation, medications to stimulate appetite, and anti-emetics [53]. Early intervention is important to maintain good QOL for patients with lung cancer.

Cancer-related fatigue has been reported in four out of five patients with lung cancer [55].

Assessment for ongoing fatigue, especially following disease-focused treatments, is essential as it can have a strong negative impact on QOL. Treatments incorporate improving psychosocial experiences, increasing physical activity for short periods, sleep hygiene, and medications such as modafinil or antidepressants.

Haemoptysis is more common in lung cancer than in other respiratory diseases and is always a distressing symptom of the disease and its treatment, increasing anxiety in the patient and caregivers. Symptom management might involve positioning the patient with the affected lung dependent to decrease blood flow, medications such as anticoagulants or antifibrinolytics may be useful, or interventions such as coagulation therapies [53]. Palliative care often includes reassurance, and discussion of prognosis to share decision making about ongoing care/treatments. Palliative management of the environment to be less frightening might include dressing the patient in dark clothing and using dark sheets and towels to avoid the red on white appearance of bleeding.

Cough, with or without production of sputum, is a bothersome symptom of many respiratory diseases. It is the body’s attempt to clear the airways and when it becomes chronic and intractable, it is debilitating, both physically and psychologically [56]. Common antitussives may offer some relief; however, determining the cause offers the best chance to relieve this symptom. Removing irritants such as smoke or other environmental pollutants is important. If an angiotensin-converting enzyme inhibitor is the cause and can be stopped, improvement is often seen in a month. Asthma or COPD may be comorbidities and may be helped by bronchodilators such as β_2 -agonists. Allergic causes of cough may respond to nasal sprays and decongestants like pseudoephedrine, and inhaled corticosteroids or antibiotics may be needed. Systemic opioids can be effectively used for cough control, especially for intractable cough. Control of purulent sputum with cough may require antibiotics.

Addressing physical pain management, which is frequently a symptom of lung cancer, includes individualised medications such as nonsteroidal anti-inflammatory drugs, opioids and bisphosphonates if there is bone involvement. Effective pain management with opioids entails attaining adequate analgesia without undue adverse side-effects. According to adapted WHO guidelines [57, 58] and the European Association for Palliative Care (EAPC) guidelines [59], morphine is the step 3 opioid of choice to achieve effective pain control in most patients. In a few patients pain relief without extreme adverse effects may need alternative opioids, spinal administration of analgesics or non-drug methods of pain control such as nerve blocks. Pain is not just a physical symptom, but includes social, psychological and spiritual dimensions, and assessment is best if the

patient can actively be involved in assessing each dimension [60].

Psychosocial discomfort is usually greatest immediately following diagnosis, at times of exacerbation and at the end of life. Clinicians should plan for active surveillance for manifestations of depression in both patients and caregivers. Advanced care planning is a key component of palliative care and can be helpful in identifying patient and family emotional needs and values [18]. Clinician/patient/caregiver communication must be clear and facilitate the understanding of options for treatment or non-treatment as well as enhanced family well-being. Coordination of services can also contribute to decreasing anxiety for patients and caregivers. Addressing spiritual feelings, requests and needs can help address uncertainty and spiritual distress. Professionals trained and skilled in addressing these needs should be in the palliative care team.

What are the main reasons to include palliative care for patients with respiratory disease?

Patient

Because of the concomitant physical and psychosocial challenges of respiratory diseases, single disease-oriented clinical guidelines are not adequate for management of care where patients have significant symptom burdens, psychosocial problems including anxiety and depression, low QOL and distressing suffering at death [20]. There is a need for patient-centred care to achieve optimal management in terms of the disease and its impact on patients and their families/caregivers, especially towards the end of life. Caregivers appreciated palliative care use and contact with the palliative care team in supporting patients at home and patients were satisfied that palliative care helps them feel supported after hospital discharge giving them confidence, so care is ongoing and symptom-management can be improved. Early introduction of palliative care decreased suffering and provided a communication conduit among clinicians, patients and their families/caregivers.

Family/caregiver

Difficulty in communication has been one of the greatest concerns for families/caregivers with a desire to know accurate information about the patient's condition and what to expect. The literature reports no respondents stating that they received too much information about the patient's condition [18, 31]. Palliative care team members were seen as patient advocates and good communicators. The assistance of palliative care clinicians in helping patients to be involved in symptom management and relief of suffering was highly valued.

Clinician

Palliative care supported discussions/conversations that truly addressed patient/family preferences in a caring and supportive manner, while providing an opportunity for perhaps difficult end-of-life planning. With training and team support, tensions between remaining hopeful and presenting realities in terms of a patient's condition can be better addressed [61].

Healthcare system

Early use of palliative care services had benefit in terms of improving care for patients with respiratory diseases, and supported cost savings in moving away from ineffective curative and restorative care to enhanced quality of living for patients and their families. Evidence of benefits is needed to develop systems and policy changes. LANKEN *et al.* [60] have prepared a seminal policy statement that addresses multiple components of palliative care for patients with respiratory diseases. REINKE and MEIER [21] have identified research needed to support policies promoting access to palliative care as well as provide evidence of quality and safety that can support reimbursement to healthcare systems.

What are the limitations and challenges of palliative care in management of patients with respiratory disease?

Assessment

It is never too early for clinicians to introduce a discussion of palliative care with patients and their families [60]. Ongoing evaluation of symptoms, responses to symptom management, knowledge of the disease and the patient's perception of their QOL and health status are all components of the assessment needed for quality palliative care. Multiple tools are available and that in itself is a challenge - identifying what to assess, when and how will need ongoing dialogue.

Intervention

Specialised palliative care services have demonstrated impact on patients QOL, especially in advanced care planning for disease progression and end of life. However, adding another team to an already complex, often fragmented system can be ineffective. It is critical to keep the patient and family at the centre of care, with palliative care integrated across the disease trajectory from diagnosis to death [62]. Care planning is challenged to include patient and family preferences, in-depth communication, responsiveness to needs in a timely manner, and proactive collaboration with ongoing assessment and monitoring of service use to enhance patient self-management and confidence and decrease

Table 4 Checklist for clinicians based on domains of palliative care

Domain	Clinician activity
Structure and processes of care	Provide patient-centred care based on patient/family goals and values. Apply research to inform evidence-based practice. Develop a network with palliative care professionals/teams.
Physical aspects of care	Set up a format for palliative care consultation visits to address patient/caregiver needs, use planned assessment questions to identify needs, address advanced care planning as ongoing, document palliative care discussions and decision in the electronic record, and document outcomes, including visit frequency, satisfaction with care, and place and manner of death.
Psychological and psychiatric aspects of care	Coordinate care across settings (primary care, emergency care, long-term care, etc.) to enhance patient/family communication and address psychological concerns as well as physical care.
Social aspects of care	Designate palliative care team members with training on collaborative assessment and interdisciplinary communication skills to identify patient and family strengths and incorporate evidence-based care practices. Provide ongoing education.
Spiritual, religious, and existential aspects of care	Assess and provide support to address spiritual concerns throughout the disease trajectory, with care designed to promote practices for comfort and relief of suffering, including referrals such as to pastoral care or other spiritual advisors.
Cultural aspects of care	Become knowledgeable about local healthcare settings and resources; provide linguistic competence in service delivery.
Care of the patient at the end of life	Plainly communicate to patients and families how to recognise signs and symptoms of the process of dying. Bereavement support begins with recognition and communication to patient/family about prognosis (e.g. hours to days) and support for anticipatory grieving.
Ethical and legal aspects of care	Always consider advanced directives in practice. Acknowledge legal and regulatory issues with access to legal counsel supported.

Information from [20].

suffering. Referral to palliative services requires prudent use of resources to be accessible.

Lessons learned

It is never too “early” to introduce palliative care for patients with respiratory diseases. Nevertheless, detailed attention to planning is needed for introducing palliative care into varied settings. A recent study implementing palliative care into a real-world community practice identified the need to adapt palliative care support to the existing work settings [63]. To support sustainability, assessment tools, planning forms and educational programmes need to be tested in the actual practice settings to decrease patient and caregiver burden and truly integrate the palliative care team into the system of care. Implementation was facilitated by communication of administrative support, and preparation to increase readiness and adaptability within the setting before introducing integrated palliative care. Barriers to implementation comprised rapidly changing disease-focused care and an unrecognised need for palliative care support by patients and providers, as well as staffing limitations, and processes dependent on staff who were not cross-trained.

A checklist for quality palliative care (table 4) may help clinicians incorporate a revised approach to

practice. Beginning patient-centred discussions to set goals for care should progress to advanced care planning and transition to end-of-life conversations. Regulatory issues must be considered and designed into palliative care protocols. As palliative care programmes are planned and implemented, there will be a constant need to re-evaluate and investigate new options. Finally, implementing a palliative care service requires consideration of human factors and related organisational characteristics that involve cultural, educational and motivational aspects of the patient/family and clinicians who are at different levels of the healthcare systems.

Summary

Based on the demonstrated effectiveness of palliative care in the alleviation of symptoms and enhancement of QOL, there is a strong movement to incorporate palliative care into the treatment of patients with a wide range of illnesses, and in various healthcare settings early in the disease trajectory (e.g. ICU, nursing homes). The American Society for Clinical Oncology and the EAPC are dedicated to the promotion and development of palliative care throughout the USA and Europe. They lead the way in publishing recommendations and

guidelines indicating that treatment of all cancer patients with symptoms or advanced disease should include palliative care throughout the illness trajectory. They influence, encourage and advocate the need for high quality palliative care throughout the life span by developing and sharing palliative care research, policy, education and evidence-based practice.

Using palliative care, patient satisfaction is high, while provider satisfaction is often ambiguous based primarily on a fear of eliminating the patient's feeling of hope. Nevertheless, the application of palliative care in practice has been effective, especially when introduced into systems that lacked a clear programme for delivery of patient-focused holistic care in a team-based model. FERRELL *et al.* [64] have designed a palliative care intervention to support patients in phase 1 clinical trials, with a detailed list of components for understanding the disease, symptom management, decision making and referral components for a quality palliative care programme. Considering the value of improved QOL and a peaceful death, improving access to palliative care for patients with respiratory diseases will benefit patients, clinicians and society.

As detailed descriptions of palliative care in respiratory disease are beyond the scope of one article; the reader is referred to the ERS Monograph

Educational questions

- 1) All of the following are components of the definition of palliative care except:
 - a) is an approach that improves the QOL of patients and their families
 - b) is not appropriate for patients with serious or life-threatening illness
 - c) is designed for prevention and relief of suffering
 - d) includes assessment and treatment of pain
- 2) Is the following statement true or false? Many patients living at home could benefit from palliative care; it is never too early to include the palliative care discussion as part of a patient visit at the time of or following diagnosis.
 - a) True
 - b) False
- 3) The domains of palliative care include all of the following except:
 - a) Structure and outcomes of care
 - b) Psychological and psychiatric aspects of care
 - c) Spiritual, religious, and existential aspects of care
 - d) Care of the patient at the end of life

on Palliative Care in Respiratory Disease [53] and the accompanying articles on aspects of palliative care in this issue of *Breathe* for further information.

Conflict of interest:

None declared.

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Suggested answers

- 1) b.
- 2) a.
- 3) a.

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