

# Role of Palliative Care in Improving the Quality of Life in Elderly with Advanced Lung Disease

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**Abstract** The traditional “either cure or comfort” approach does not optimize palliative care in elderly with advanced lung disease. Instead, a holistic, patient-centered, “comfort and cure together” approach with palliative and best care practices integrated as needed across the entire illness course will improve quality of life and other outcomes in these patients and their families. Competency in primary palliative care, identification of patient and family vulnerability, care plans formed by patient-centered communication, timely palliative responsiveness, and effective advance care planning are key components that support this approach. Dependency of patients on emergency or in-patient care for crisis of dyspnea and other symptoms is costly. To resolve this issue, a proactive, collaborative management with appropriate and carefully monitored use of opioids and other treatment is recommended. A revised primary care—integrating palliative care to curative/restorative care and judiciously referring to specialist palliative care—is essential for sustainable improvement in palliative care delivery.

**Keywords** Palliative care · Quality of life · Geriatric · Elderly · Aged · Advanced lung disease · Respiratory disease · Critical illness · Chronic obstructive lung disease · Interstitial lung disease · Lung cancer · Health care for the aged · Quality of health care · Hospice care · Terminal care · End-of-life care · Bereavement care · Symptoms · Dyspnea · Pain · Psychological and spiritual distress · Suffering · Education · Training · Research

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## Abbreviations

ACP	advance care planning
COPD	chronic obstructive lung disease
FEV1	forced expiratory volume in one second
ILD	interstitial lung disease
PC	palliative care
pO <sub>2</sub>	partial pressure of oxygen
QoL	quality of life
VC	vital capacity

## Introduction

Currently, elderly population is increasing in many countries. The pattern and course of the disease change in the elderly that usually live with serious chronic respiratory and circulatory diseases as well as with cancer. Thus, more elderly people will require help at the end of life within a social environment of changing family structure besides wider migration, employment, and aging of caregivers. Although there is evidence of significantly increased need for palliative care (PC) worldwide, there has been relatively insufficient attention and progress in this area regarding health policy and research. It is well established that simple measures are effective in the areas of the unmet needs of elderly, such as symptom relief, information, communication, and preferences for place of care [1, 2•, 3, 4•, 5••]

Outcome data of coordinated team care, home nursing, and specialist PC are obtained mostly from studies in patients with lung cancer or other malignant diseases. For the elderly with other serious lung diseases such as chronic obstructive lung disease (COPD) and pulmonary fibrosis secondary to interstitial lung disease (ILD) or other disorders, there are gaps in the evidence-based PC. However, in many of these nonmalignant cases, the needs and solutions most probably will be similar to those in patients with malignancy [1, 2••]

PC is a multidisciplinary or interprofessional approach focused on holistically improving the quality of life (QoL) of all patients and their families facing the problems related to active, progressive, and far-advanced disease, by preventing and relieving physical, psychosocial, and spiritual suffering. Maintaining and improving the QoL in any stage of illness—acute, chronic, or terminal—is the main target in the practice of PC which is based on patient and family preferences, not concerned with life prolongation or shortening or long-term disease remission, and is appropriate for patients receiving continuing therapy for their underlying disease [1, 2•, 3, 4•, 5•] The core components of PC in the elderly, given below, are the same as those in younger adults [2•, 3, 4•, 5•, 6]:

- Identification of the patient with need for PC
- Assessing physical and psychological symptoms
- Management of physical symptoms
- Management of psychological and spiritual distress and suffering
- Expert, effective communication to establish goals of care
- Assisting with complex decision making
- Delivery and coordination of care

For advanced lung diseases, consensus statements and guidelines from medical societies encourage a holistic, collaborative, and integrated care in palliation. As an expert opinion from practice leaders, the traditional “either cure or comfort” approach of starting PC after failing curative/restorative care does not benefit patients with advanced lung disease, or their families regarding QoL. If there is a need, PC can and should be offered concurrently with disease-directed and curative treatments, beginning from the time of diagnosis, across entire illness trajectory including hospice care, and encompassing bereavement care for the family after death. This “cure and comfort together” approach should always be based on constitution of primary PC competencies, identification of specific vulnerability related to advanced lung disease, and description of the PC plans formed by patient-centered communication, timely palliative responsiveness, and plans of effective advance care [2•, 3, 4•, 5•].

The dependency of advanced lung disease patients on emergency department or in-patient care for preventable episodic crises of dyspnea, pain, and other symptoms causes extremely high human and financial costs. To resolve this issue, a concept of “collaborative case management, appropriately and carefully monitored use of opioids and other treatment as indicated, integration of PC to standard care and referral to specialist PC services when required” is strongly encouraged by experts and leaders in the field [2•, 3, 4•, 7].

Ideally, all clinicians caring for chronic or advanced respiratory diseases and/or critical illnesses should be trained to be capable of providing recommended basic competencies in PC.

However, they should appropriately consult with PC specialists when PC situation exceeds their competence. Furthermore, practical recommendations of PC from the statements of official medical societies are useful to guide clinicians. These recommendations are on management of common symptoms and complications, psychological challenges due to suffering and dying, managing these challenges, and multidisciplinary hospice care [2•, 3, 8, 9].

### Identification of Patient with Need for Palliative Care

To improve holistic assessment and care planning, the first step in PC is and should be identifying the appropriate patient with unmet needs. For this purpose, disease-specific prognostic parameters/markers are less helpful on an individual basis although they can predict mortality. The easiest and most practical way of identifying a patient for PC is considering whether the death of the patient within 6–12 months would medically be no surprise [1, 2•, 3, 6]

Clinical signs of advanced lung disease for hospice eligibility are given below:

- Disabling dyspnea at rest due to severe airways obstruction ( $FEV1 < 30\%$ ) or severe restrictive defect ( $VC < 60\%$ , transfer factor  $< 40\%$ ),
- Progression of end-stage lung disease as manifested by increased hospitalizations or visits to emergency department for infective exacerbations or respiratory failure,
- Hypoxemia at rest on ambient oxygen ( $pO_2 \leq 55$  mmHg) or other blood gas parameters meeting criteria for long-term oxygen therapy,
- Right heart failure due to lung disease (cor pulmonale), unintentional progressive weight loss and low body-mass index ( $< 21$ ), resting tachycardia, poor or deteriorating performance status, and persistent or severe symptoms

The criteria in the first three items are major and must be present while those in the fourth are supporting for PC eligibility [3, 6, 7].

### Assessment of Physical and Psychological Symptoms

Common symptoms such as breathlessness, pain, cough, fatigue, anorexia, nausea/vomiting, constipation, depression/anxiety, insomnia, and delirium should be meticulously sought for.

Validated instruments are indicated for routine symptom evaluation in advanced lung disease. Assessing with validated instruments, by optimizing symptom identification, leads to better outcomes and increased QoL as compared with

standard assessment. The same assessment scale should be used serially. Edmonton symptom assessment scale that is shorter than other symptom assessment tools can be more practical in elderly patients.

The assessment method for symptoms should be modified according to the cognitive, motor, visual, or auditory impairment frequently encountered in geriatric population. A graphic pictorial scale or a three-word descriptor scale (mild, moderate, severe) may be easier than a 0–10 visual analog scale. In cases with mild or moderate dementia, more frequent assessment is required to appropriately find and assess pain or other symptoms regarding severity. If the patient is nonverbal due to severe cognitive impairment, symptom identification is quite difficult. In this situation, symptoms are assessed by observation and through information from caregivers [1, 4•, 5•, 7]

### Management of Physical Symptoms

Symptoms in the elderly with advanced lung disease, particularly dyspnea, lead to intensive use of emergency departments, or hospitalizations. To reduce this reliance on acute emergent or in-patient care, an *anticipatory individualized action plan*, as in the COMFORT approach by the American Thoracic Society, is necessary. This action plan gives practical tips that help patients and families cope with dyspnea crises. The COMFORT and similar other customizable caregiver plans provide a written graduated course of interventions beginning with behavioral and non-pharmacologic interventions, progressing through inhaled bronchodilator treatment (if airflow obstruction exists) and careful titration of home oxygen (if indicated) and finally going up to the use of opioids and/or anxiolytics if symptoms are refractory to the previous sufficient management approaches [2•, 3, 4•, 6, 7].

For ideal symptom management, practicing a cohesive and patient-centered approach responsive to needs across illness trajectory is essential. The practical points below are critical for achieving this type of PC and thus, coping with symptoms [2•, 3, 4•, 8]:

- In both primary and specialist levels of PC, it is important to check whether the current treatment is sufficient. If not, it should be optimized and consequent effect on symptoms should be monitored closely.
- Meanwhile, preventive treatments should be reviewed if the prognosis is limited and treatment burdens exceed benefits.
- Furthermore, patient and family understanding of illness, care options, and management should be explored in detail.
- In all levels of PC, treatments of the underlying disease, infective exacerbations and any co-morbid illnesses are continued concurrently with the supportive and PC.

- Enhanced palliative competencies and best medical practices for “primary care” (pulmonary and other disciplines outside specialized PC) are required. With appropriate mentorship from and linkage to specialist PC, a team-based approach can also be achieved in primary PC.
- Specialist PC, using coordinated structured programs, provides a multidisciplinary, expert and team-based care for complex advanced cases referred from primary PC.

### Treatment of Dyspnea

*Non-pharmacological interventions* include controlled breathing and anxiety management techniques and planning and pacing activities to enhance coping and functional ability; considering needs for equipment/aids, a package of care, or financial/benefits advice; and a handheld fan if the patient is not hypoxic.

*Respiratory disease treatments* should be optimized as below:

*COPD*—Inhalers already being used are reviewed, and use of a spacer device or nebulizer is considered while inhaled long acting beta2-agonist and/or muscarinic receptor antagonist and inhaled steroid combinations are continued.

*ILD*—Immunosuppressants and long-term oral steroids should be reviewed and continued or stopped according to the indications in the current stage.

*Lung cancer*—Chemotherapy, radiotherapy, and limited resections should be reviewed and continued or stopped according to the indications in the current stage.

*Oxygen*—The recommendations from the guidelines of long-term oxygen therapy are applied [1, 2•, 3, 6, 10]

*Further medication for persistent breathlessness* in advanced lung disease is required for symptom control besides non-pharmacological interventions and standard pharmacological medication as the disease deteriorates:

- *Opioids*—Severe breathlessness and cough refractory to other treatments can be ameliorated by wise and careful treatment with opioids. When started prudently at a very low dose (30–50 % of dose for young adults) and carefully titrated upward as required, opioids are safe and do not cause respiratory depression in advanced lung disease. Sublingual fentanyl can be started at a 12.5–25-mg dose, using 50 mg/mL IV preparation, but response and side effects must be monitored closely. It should not be used in opioid-naïve patients. Other fentanyl preparations for reducing pain by buccal sprays or tablets are too strong for dyspnea. Decreased renal and hepatic function and altered body fat distribution in elderly may cause high

serum levels and side effects. Thus, potential benefits and risks should be weighed individually. However, non-pharmacological interventions that optimize symptom management are essential and should be continued besides opioid and non-opioid treatment.

- *Benzodiazepines*—Although less effective for breathlessness than opioids, benzodiazepines can decrease anxiety and panic due to breathlessness. However, they should be used as a third-line treatment for symptoms refractory to non-pharmacological interventions and opioids. Anxiety and panic cause distress, however, do not make patient's condition worse [2•, 3, 6].

### Treatment of Pain

In the geriatric population pain, if unrecognized or undertreated, can cause depression, anxiety, delirium, isolation, disturbed sleep and appetite, gait instability, and loss of functional capacity. Consequently, as the patient's QoL decreases, health care use and costs increase.

Pain can be chronic somatic or neuropathic. Chronic somatic pain in patients with advanced lung disease is most frequently associated with musculoskeletal disorders, lung cancer, or treatment of lung cancer. Etiologies of neuropathic pain include diabetic neuropathy, post-herpetic neuralgia and spinal stenosis, and tumoral involvement of nerves. In the first-line treatment of chronic somatic pain, usually non-opioid analgesics are used in nonmalignant cases and opioids for moderate to severe pain in malignant cases. If nonmalignant pain is persistent, opioids can be used. However, potential benefits and risks should be carefully reviewed. For neuropathic pain, adjuvant analgesics (gabapentin, carbamazepine, selective serotonin reuptake inhibitors, transdermal lidocaine) and opioids can be useful.

Lower initial doses of opioid (fentanyl 50–100 µg IV; morphine 2–10 mg IV, 5–10 mg PO) and non-opioid pain medications and appropriately increased dosing intervals are recommended in geriatric patients as they are more susceptible to adverse events and have decreased renal and hepatic function [1, 3, 5•, 11]

### Identifying and Supporting for Psychological and Spiritual Distress

In advanced respiratory diseases, the risk of depression, anxiety, and panic attacks is higher. Dyspnea can cause anxiety and panic attacks, but anxiety can also cause dyspnea. Psychological distress compromises QoL, decreases response to therapies during exacerbations, and increase hospitalizations. Pain-related symptoms are associated with anxiety while functional impairments are often associated with

depression which may cause the patient to discontinue curative/restorative treatment. However, the patient's preferences may change after a successful response to depression treatment. Therefore, end-of-life preferences should be reassessed after response to treatment of depression [3, 4•, 5•].

Comorbidities, social isolation, and low socioeconomic status and education levels cause vulnerability in patients with advanced lung disease and their caregivers. Dyspnea, pain, immobility, oxygen, and other breathing-related equipment limit their lives considerably. Furthermore, they are challenged with significant psychological distress related to fluctuating emotions, frustration, loss of purpose and hope, fear of death, and feeling of “disadvantaged dying.” In clinical practice, there has been gaps in attention and care to be given to this vulnerability and accompanying psychosocial and spiritual suffering although PC-related guidelines emphasize and support it. Besides physical needs, emotional, social, and spiritual needs of the patient and caregivers can only be met by a plan of *patient-specific education and support* in making decisions that respect patient's needs and wishes. This plan should be made with partnership of the patient, caregivers, and health care providers through effective communication [2•, 3].

The relationship of spirituality and religious practice to outcomes in seriously ill patients have been studied in observational and cohort studies. More hospice care is received and less non-beneficial interventions are performed near the end of life in patients with supported spiritual needs. On the other hand, patients who believe in religious faith to cope with disease are more likely to receive intubation and intensive care unit care near the end of life. Unmet spiritual concerns can lead to worse psychological QoL compared with addressed spiritual needs. Moreover, spiritual support from the medical team or chaplain increases QoL scores. Consensus supports referral to a chaplain for spiritual concerns. However, the efficacy of spiritual interventions and how spiritual distress affects outcomes has not been studied specifically [4•, 12, 13].

### Expert Communication to Establish Goals of Care

Giving “breaking bad news,” discussing prognostic uncertainty, establishing goals of care, and selecting treatment options in advanced lung disease requires effective and structured communication. Research focused on communication in serious illness have shown that communication training improves clinical outcomes and increases overall family satisfaction with intensive care and decision-making. After a structured discussion with the physician about goals of care, advanced cancer patients less likely wish to have mechanical ventilation and cardiopulmonary resuscitation or die in an intensive care unit but to be cared in a hospice.

Core communication skills can be achieved through training online or in workshop settings. These training programs provide a clear outline (*SPIKES: how to set up discussion, evaluate patient's perception, get patient's invitation, give knowledge and information, responding to emotion, and summarizing the discussion*) and core skills for effective communication with empathy (*NURSE: naming, understanding, respecting, supporting, exploring*). Communication training is particularly useful for clinicians developing skills in primary PC and wishing to involve patients in advance care planning [4••, 14–16].

### Assisting with Decision-Making

Elderly with advanced lung disease can usually be able to decide early in the course of the disease. Thus, determining their goals of care in the immediate and long term besides identifying the person to make decisions on their behalf, when necessary, are important. A sensitive and sincere discussion should be guided by goals, preferences, and questions of the patient. Benefits and drawbacks of life-prolonging treatments (mechanical ventilation, lung transplantation, phase I or II clinical trials, etc.) should be discussed. Decision on PC is made after several discussions.

There are three components of decision-making at the end of life:

- *Informing the patient or surrogates*
- *The patient's or surrogate's decision to receive only/primarily PC*
- *Coordinating and providing PC*

Discussions should involve the patient, family members, and health care team. Involvement of the health care team in decision-making—in an advisory, shared, or primary decision-making role—should be determined by the preferences of the patient or surrogates [2••, 3, 17].

### Patient-Centered Advance Care Planning

As an organized and ongoing communication process and *not a last-minute decision-making*, advance care planning (ACP) helps the patient express and discuss beliefs, goals, and priorities to guide decisions of care until and including end of life. A trained facilitator (not necessarily a physician) skilled in communication, caregiver(s), and/or a delegate decision-maker are involved in ACP. In ACP discussions, key points are listening more than talking, verbalized empathy, clarification or information, decisional readiness, and facilitating understanding for informed choice. Having these discussions at patient's home, if possible, increases accessibility, comfort level, and care experience [2••, 3, 18, 19].

## Delivery and Coordination of Care

### Hospital-Based Care

Non-hospice PC is most commonly given in acute care hospitals in many parts of the world. Within hospitals, the primary model of care delivery is the interdisciplinary consultation team. There may be in-patient units of PC in large hospitals and developed programs. Novel hospital-based PC delivery models are comanagement models—a PC specialist joining a specialty team, dedicated ICU teams, and triggers for automatic PC referrals. Related studies have shown that hospital-based PC reduces symptom and spiritual distress, costs, and resource utilization besides enhancing QoL in seriously ill patients [4••, 20].

### Community-Based Care

Currently, this model of PC is delivered through traditional hospice programs and new community-based models of PC. Hospice is only available in home-based settings to patients with a survival of 6 months or less and who decide to forgo curative treatments. New community-based models of PC can serve seriously ill people who are not eligible for hospice. These programs are rapidly evolving within commercially managed, cost-sharing, and bundled-payment health care programs. Based on the core components of PC, they provide interdisciplinary PC teams, caregiver support in home setting, coordination of PC, and support to treating physician. Evidence from trials show improved symptoms and patient and family satisfaction and reduced hospitalization rates, emergency department visits, days in the intensive care unit, and physician office visits with the use of these new programs. They also appear to increase survival, but this has to be investigated further. Community-based PC services are well-developed in Western Europe, Canada, and Australia [3, 4••, 21•, 22].

### Long-Term Care

Nursing homes give long-term PC in three different models: hospice, PC consultation, and internal PC teams/specialized units. Hospice, the most established model, has reduced invasive therapies and hospitalizations and improved symptoms and family satisfaction with care. However, 6-month survival requirement is a limitation. The other two models have limitations regarding reimbursement, training, or patient population [4••, 23].

## Effective Integration into New Models of Palliative Care

Transforming PC of chronic lung disease from reactive to anticipatory care through collaborative work of the primary PC team with patients and caregivers can be possible within a framework of “patient-focused medical home.” Redesigning the system, optimizing clinical information systems, supporting physicians in decision-making, and patient self-management are the core components of this framework. It is evidence-based that integrating two or more components of chronic care model leads to significantly reduced hospitalization rates, lengths of stay, emergency/unscheduled outpatient department visits, and costs [2•, 24–26].

A novel and supportive program of individualized care for patients with respiratory diseases and their families (INSPIRED) suggests that a multidisciplinary outreach program focused on PC across care transitions can support patients who wish to die at home. Collaborative work of respiratory therapists and PC and spiritual care practitioners can enable some patients to stay home longer. Practical community- and home-based palliation of INSPIRED currently being performed and assessed in Canada can provide more “both/and” or “comfort and cure together” approach to effective PC for patients with advanced lung disease [2•, 27•, 28•].

Deficiencies in continuity, communication, and collaboration among health professionals besides uncertainties regarding disease course are currently the main barriers to effective PC delivery. Commitment of professional societies and funders to support and sustain innovative approaches is required in overcoming these deficiencies. Patients and families involved in the management of respiratory distress, uptake of new knowledge among colleagues in PC team, and combining evidence-based medicine with quality improvement are musts for shifting from traditional to novel PC. Models of care may vary depending on local medical culture, expertise, and resources [2•, 3, 4•, 28•, 29–31]. However, key components of successful PC delivery are listed below [2•, 3, 4•, 5•]:

- Dedicated and skilled case manager,
- Advance care planning,
- Follow-up at home and access to physician if needed,
- Access to medical support after-hours: from 24 to 7,
- Personalized action plan to manage dyspnea and other symptoms
- Support and education at home by a skilled PC educator/therapist
- Direct hospitalization bypassing the emergency if indicated
- Home support and personal care
- Accessible care for family caregivers
- Linkage to hospice at home for end-of-life care
- Access to specialist with respiratory and PC expertise

## Conclusion

Models with specific interventions and holistic approaches in PC can improve outcomes in elderly patients and their families living with the burdens of advanced lung diseases. Expansion of specialist PC services or a more integrated approach by institutions or organizations will help patients and their families reach informed decisions about their care throughout the course of disease. Establishing PC capacity within primary care is essential to provide more holistic, responsive, and sustainable PC in advanced lung disease. Furthermore, training pulmonologists and other branch specialists in symptom management, particularly dyspnea; communication; ACP; and PC coordination is another must. Within the spectrum of care, medical treatment focused on survival and holistic PC focused on QoL should be given concurrently but a change in the intensity of each across the disease course will be needed.

## Compliance with Ethical Standards

**Conflict of Interest** Semra Bilaceroglu declares that she has no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by the author.

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