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AMERICAN THORACIC SOCIETY DOCUMENTS

Palliative Care Early in the Care Continuum among Patients with Serious Respiratory Illness An Official ATS/AAHPM/HPNA/SWHPN Policy Statement

Donald R. Sullivan, Anand S. Iyer, Susan Enguidanos, Christopher E. Cox, Morag Farquhar, Daisy J. A. Janssen, Kathleen O. Lindell, Richard A. Mularski, Natasha Smallwood, Alison E. Turnbull, Anne M. Wilkinson, Katherine R. Courtright, Matthew Maddocks, Mary Lynn McPherson, J. Daryl Thornton, Margaret L. Campbell, Tracy K. Fasolino, Patricia M. Fogelman, Larry Gershon, Thayer Gershon, Christiane Hartog, Judy Luther, Diane E. Meier, Judith E. Nelson, Elliot Rabinowitz, Cynda H. Rushton, Danetta H. Sloan, Erin K. Kross*, and Lynn F. Reinke*; on behalf of the American Thoracic Society, American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, and Social Work Hospice and Palliative Care Network

THIS OFFICIAL POLICY STATEMENT OF THE AMERICAN THORACIC SOCIETY (ATS), AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE (AAHPM), HOSPICE AND PALLIATIVE NURSES ASSOCIATION (HPNA), AND SOCIAL WORK HOSPICE AND PALLIATIVE CARE NETWORK (SWHPN) WAS APPROVED BY THE ATS, AAHPM, HPNA, AND SWHPN MAY 2022

Abstract

Background: Patients with serious respiratory illness and their caregivers suffer considerable burdens, and palliative care is a fundamental right for anyone who needs it. However, the overwhelming majority of patients do not receive timely palliative care before the end of life, despite robust evidence for improved outcomes.

Goals: This policy statement by the American Thoracic Society (ATS) and partnering societies advocates for improved integration of high-quality palliative care early in the care continuum for patients with serious respiratory illness and their caregivers and provides clinicians and policymakers with a framework to accomplish this.

Methods: An international and interprofessional expert committee, including patients and caregivers, achieved consensus across a diverse working group representing pulmonary–critical care, palliative care, bioethics, health law and policy, geriatrics, nursing, physiotherapy, social work, pharmacy, patient advocacy, psychology, and sociology.

Results: The committee developed fundamental values, principles, and policy recommendations for integrating palliative care in serious respiratory illness care across seven domains: 1) delivery models, 2) comprehensive symptom assessment and management, 3) advance care planning and goals of care discussions, 4) caregiver support, 5) health disparities, 6) mass casualty events and emergency preparedness, and 7) research priorities. The recommendations encourage timely integration of palliative care, promote innovative primary and secondary or specialist palliative care delivery models, and advocate for research and policy initiatives to improve the availability and quality of palliative care for patients and their caregivers.

Conclusions: This multisociety policy statement establishes a framework for early palliative care in serious respiratory illness and provides guidance for pulmonary–critical care clinicians and policymakers for its proactive integration.

Keywords: quality of life; caregivers; healthcare disparities; advance care planning; lung diseases

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<p>Contents Introduction Methods Palliative Care Domains I. Delivery Models</p>	<p>II. Comprehensive Symptom Assessment and Management III. Advance Care Planning and Goals of Care Discussions IV. Caregiver Support</p>	<p>V. Health Disparities VI. Mass Casualty Events and Emergency Preparedness VII. Research Priorities Conclusions</p>
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Introduction

Palliative care is specialized medical care for people living with serious illness and focuses on providing relief of distressing symptoms and improving the quality of life (QOL) for both the patient and their family. Palliative care is distinct from hospice care, which focuses on care delivered at the very end of life, whereas the integration of palliative care is appropriate at any stage of a serious illness and is most beneficial when provided in conjunction with curative or disease-modifying treatments. Palliative care delivery is the responsibility of all clinicians caring for patients with serious respiratory illness. In 2008, the ATS (American Thoracic Society) published a policy statement on palliative care for patients with respiratory disease and critical illness (1). That policy statement described barriers to receiving comprehensive palliative care and called on the ATS to work with other professional societies to support palliative care, enhance education, and encourage funding of palliative care research to provide best practices. Since then, there has been significant growth in the field of palliative care (2), yet barriers to palliative care remain, especially outside of hospitals and in communities where patients with serious respiratory illness are living and receiving medical care.

This policy statement focuses on people living with serious respiratory illness (e.g., chronic obstructive pulmonary disease [COPD], interstitial lung disease [ILD], and lung cancer) who often have a chaotic end of life, seeking relief from debilitating symptoms such as breathlessness in acute care settings and receiving fragmented and burdensome care that may not be aligned

with their values and wishes. Even in high medical resource settings, palliative care is underresourced, particularly in outpatient settings, and cannot meet the needs of patients and their families (3, 4). This is especially concerning in rural settings (4) and developing countries, where 86% of the global population lacks access to the highest degree of palliative care (5). Given the persistence of these known deficiencies for decades, coupled with the anticipated doubling of the burden of serious health-related suffering expected by 2060 (5), a concerted effort to increase the accessibility and quality of palliative care in pulmonary and critical care medicine is urgently needed.

There are several important definitions used by the committee in this policy statement (Table 1). There are three distinct levels of palliative care on the basis of clinician training, care complexity, and setting (primary, secondary or specialist, and tertiary palliative care) (9, 10) (Figure 1). In this statement, we also discuss serious respiratory illness (6) and the importance of caregivers who provide support for the medical needs or daily activities of patients. This policy statement is intended to build on previous ATS work to 1) encourage timely, integrated palliative care in respiratory illness, highlighting current evidence; 2) review and promote innovative primary and secondary or specialist palliative care delivery models; and 3) advocate for research and policy initiatives to improve the quality and availability of palliative care in pulmonary and critical care medicine. The committee used a values- and principles-based approach (Table 2) to derive recommendations designed to provide a framework and identify policy priorities for palliative care integration among patients with serious respiratory illness.

- **Recommendation 1:** The spectrum of palliative care in serious respiratory illness begins with primary palliative care delivered by pulmonary and critical care clinicians that is integrated concomitantly with usual disease-modifying therapies and should be complemented by interprofessional secondary or specialist palliative care expertise when necessary.
- **Recommendation 2:** Comprehensive, individualized assessment of symptoms and needs should occur at every routine clinical encounter.
- **Recommendation 3:** Advance care planning should be an iterative and longitudinal process of communication that starts at the diagnosis of a serious respiratory illness and evolves with changes in patient health status, goals, and preferences.
- **Recommendation 4:** Informal caregivers should be identified and incorporated as a part of the primary unit of care with patients; effective engagement is necessary to support both patients and informal caregivers throughout the illness journey, including respite and bereavement.
- **Recommendation 5:** Comprehensive primary palliative care training of pulmonary–critical care clinicians is essential and can help mitigate disparities in access; this should begin early in professional training and includes elements such as palliative care terminology and communication, advance care planning, active listening, cultural awareness and sensitivity, and symptom assessment and management.

Dedication: This document is dedicated to ATS past-president J. Randall Curtis, M.D., M.P.H., the father of palliative care in pulmonary and critical care medicine, whose fierce leadership and tireless efforts in critical care medicine, research, and policy on behalf of his patients and their families inspire us to continue his legacy. Randy’s generosity, humility, enthusiasm, compassion, and courage, as well as his sage advice and mentorship, have guided the careers (and sometimes lives) of many members of this committee, and we are forever indebted to him. Most importantly, his example reminds us to prioritize the things we love.

Table 1. Policy Statement Definitions

Serious respiratory illness (6)	A respiratory condition (e.g., chronic obstructive pulmonary disease, pulmonary hypertension, interstitial lung disease, lung cancer, etc.) that carries a high risk of mortality and symptom burden (e.g., dyspnea and depression) and either negatively impacts a person’s daily function or quality of life or negatively impacts their caregivers.
Hospice care	This care is not synonymous with palliative care. Hospice care is specialized care for people who are experiencing a life-limiting illness and their caregivers so that they may live as comfortably as possible. The hospice philosophy accepts death as the final stage of life but does not try to hasten or postpone death. Bereavement services and respite care (i.e., short-term relief) for families are a core component of this care. Settings can include inpatient units, community facilities, and in-home care or a combination of these on the basis of needs. In the United States, the Centers for Medicare and Medicaid Services provides a hospice care program for people with a life expectancy of 6 mo or less.
ACP	This is a process that supports persons “at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness” (7).
GOC discussions	This term is sometimes used in a narrow sense, specifically referring to discussions regarding resuscitation preferences or “code status” during hospitalizations. This policy statement employs a broader definition of this term, meaning any discussions and/or decisions regarding specific treatments, the intensity of care, and future planning for care, including values, goals, and preferences elicitation. GOC discussions are expected to occur across healthcare settings and are considered an important component of ACP.
Informal caregiver or caregiver	A person (e.g., partner, family member, or friend, among others) who provides unpaid support for the medical needs or daily activities of someone living with a serious respiratory illness. This committee acknowledges that this terminology frames these individuals only in terms of the patient and the patient’s needs and does not encompass the totality of caregiver responsibilities, contributions, or their own need for more individualized support and recognition.
Surrogate	A person designated to make decisions related to the health care of an individual in the event that he or she is unable to do so (i.e., the patient is incapacitated). This person could be designated in a legal document called an HCPA. The HCPA refers to both the legal document and the person designated to make healthcare decisions. In lieu of a legal document, there are state-specific guidelines for who is the legally recognized person able to make health decisions (e.g., spouse, adult child, etc.). Surrogate decisions are often guided by the substituted judgment principle, in which a surrogate should attempt to determine what the patient would have wanted under the given circumstances or what the patient would have decided if he or she were competent to choose (8).
Types of palliative care (9, 10)	
Primary	Care is provided by clinicians who are trained in basic tenets of palliative care but are not palliative care specialists (e.g., pulmonary and critical care clinicians, primary care clinicians, etc.).
Secondary	Care provided by trained palliative care specialists (e.g., nurses, physicians, advance practice providers, social workers, chaplains, etc.). This care is sometimes referred to as specialist palliative care.
Tertiary	Care provided by trained palliative care specialists at tertiary and quaternary medical centers and includes caring for the most complex patients. This may include care in dedicated palliative care units.

Definition of abbreviations: ACP = advanced care planning; GOC = goals of care; HCPA = medical or healthcare power of attorney.

- **Recommendation 6:** Emergency response planning and preparedness should include provisions for the delivery of palliative care in the context of a catastrophic event and/or resource limitation. The palliative care response must include both the existing and new vulnerable populations who will be most impacted by a catastrophic disaster and should consider eight critical elements of crisis palliative care provision: staff, staff, space, systems, sedation, separation, communication, and equity.
- **Recommendation 7:** Pulmonary–critical care and palliative care

professional societies should create a Pulmonary Palliative Care Research Consortium to support collaborative research opportunities with associated funding mechanisms to advance pulmonary palliative care science.

Methods

A diverse international, interprofessional committee from relevant disciplines developed this policy statement using an iterative approach. Project co-chairs invited international experts to join the committee to

ensure the full working group was diverse and represented a breadth of professionals (e.g., nurses, patients, caregivers, pharmacists, physicians, physiotherapists, social workers, and researchers), disciplines (e.g., pulmonary–critical care, palliative care, bioethics, law and policy, geriatrics, nursing, physiotherapy, social work, pharmacy, patient advocacy, psychology, and sociology), and specific content area expertise (e.g., advance care planning and informal caregivers). In addition to a core of ATS Behavioral Science and Health Services Research Assembly members, the co-chairs solicited representation from the following

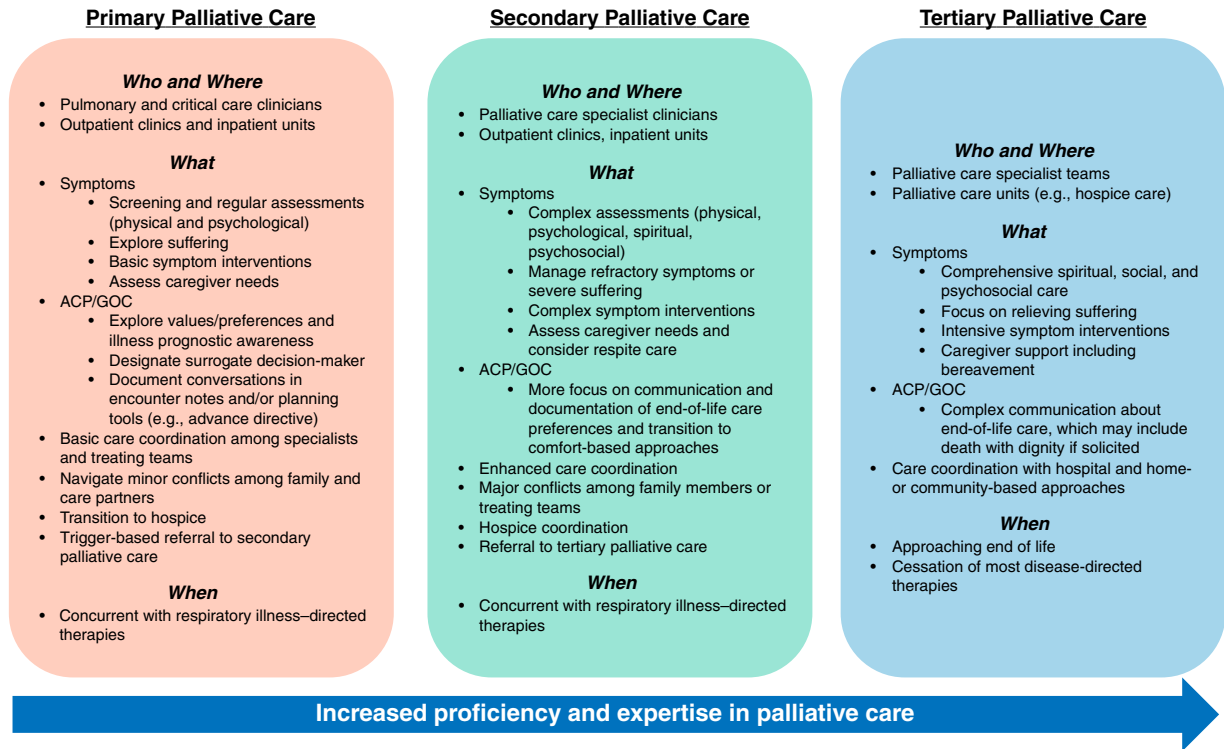


Figure 1. Levels of palliative care. This figure illustrates the who, where, what, and when of palliative care across three levels of increasing proficiency and expertise (primary, secondary or specialist, and tertiary palliative care). ACP = advanced care planning; GOC = goals of care.

ATS groups: Patient Advisory Roundtable, Nursing Assembly, Health Policy Committee, Ethics and Conflict of Interest Committee, Critical Care Assembly, and Patient and Family Education

Committee to ensure balanced advice and input from a variety of perspectives. To achieve the greatest potential impact in the field, representatives with expertise in serious respiratory illness from the

following national stakeholder societies were also solicited: AAHPM (American Academy of Hospice and Palliative Medicine), CAPC (Center to Advance Palliative Care), HPNA (Hospice and

Table 2. Fundamental Values and Principles of Palliative Care in Serious Respiratory Illness

1. All patients with serious respiratory illness are eligible for palliative care on the basis of needs and should have equitable access, regardless of demographic characteristics (e.g., race/ethnicity, LGBTQIA+, age, sex, houselessness, and citizenship status), geographic area of residence, stage of illness, or insurance status.
2. Primary and secondary or specialist palliative care should be provided throughout the course of the illness when needs arise, integrated with illness-directed treatment, and should not be limited to patients in the final months or weeks of life.
3. Palliative care approaches include assessment and management of physical, psychosocial, ethical, and spiritual/existential domains; therefore, this care should be interprofessional and engage all available and relevant disciplines.
4. Palliative care communications should be provided in the preferred language/linguistic style of patients and their caregivers, partners, or family.
5. Pulmonary and critical care clinicians should prioritize the development and ongoing maintenance of primary palliative care knowledge and skills.
6. Pulmonary and critical care professional societies should encourage a basic degree of primary palliative care knowledge and skill development among its members, which may include approaches such as serious illness communication and symptom assessment and management.
7. Policies and payment models that provide resources to facilitate palliative care delivery, including the provision of primary palliative care, are essential.
8. Palliative care should be included in healthcare disaster and pandemic planning and preparedness activities as part of local, regional, state, and federal disaster planning efforts.
9. Patients with their informal caregivers, partners, or family together are the principal unit of care to be identified, acknowledged, and effectively supported.
10. Pulmonary and critical care and palliative care professional societies should support research, training, and professional education to improve the provision of palliative care among patients with serious respiratory illness.

Palliative Nurses Association), and SWHPN (Social Work Hospice and Palliative Care Network).

Policy statement development proceeded in four phases (Figure 2). In phase one (conceptualization), the project co-chairs and selected committee members reviewed existing relevant literature, including previous ATS policies and policies of other organizations (1, 11–13), to identify subtopic domains and prepare introductory materials across these domains. Next, in phase two (preparation), small group facilitators participated in teleconferences with co-chairs to review small group structure and function. In phase three (presentation, facilitation, and exploration), presentations and small group sessions were followed by full committee discussions over two half-day virtual meetings to begin developing consensus. Small group sessions and discussions were conducted using SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis (14), followed by loose variants of the nominal group technique and Delphi techniques (15) adapted from previous work in rheumatology (16). The purpose of this process was to work toward consensus in identifying key priorities and identifying the lack of consensus (“dissensus”) where it existed. In phase four (integration and compilation), additional rounds of Delphi

techniques were used toward developing full committee consensus. The writing committee drafted the policy statement, with successive drafts reviewed by the full committee, who revised it in an iterative process. The resulting final draft was subject to review by the ATS Documents Editor, the ATS Board of Directors, and anonymous peer reviewers from cosponsoring societies, per ATS policy. Potential conflicts of interest were disclosed and managed in accordance with the policies and procedures of ATS.

Palliative Care Domains

I. Delivery Models

Palliative care has undergone a dramatic evolution since its inception in the 1960s, from primarily community-based care focused on patients approaching death toward a vision for palliative care integration concurrent with conventional disease-modifying therapies throughout the course of illness and across medical treatment settings (17, 18) (Figure 3). The benefits of secondary palliative care are unequivocal (19–22) and can be extrapolated to patients with serious respiratory illness. Today, the major delivery models of specialist palliative care include inpatient consultation teams, acute palliative care units, and ambulatory, home, or community-based outpatient services. Hybrid models also include integrated, interprofessional clinics where palliative care specialists are embedded within a pulmonary clinic (18, 23, 24). These hybrid models are often disease-focused (e.g., lung cancer) (24) or symptom-focused (e.g., breathlessness) (18, 25). Models also differ in their team structures, care processes, components, patient populations, and reimbursement. Financial incentives can influence delivery models, such as the recently introduced Centers for Medicare and Medicaid Services reimbursement codes for advance care planning (ACP) (26) and the Medicare Care Choices Model demonstration allowing concurrent curative and hospice care (27). Unfortunately, access to palliative care is limited (4, 5), particularly in outpatient settings, and the looming specialist palliative care workforce shortage will exacerbate the unmet palliative care needs of patients (3, 28). As a result, there is an increased emphasis on the holistic model referred to as primary

palliative care, or the delivery of palliative care by all clinicians who care for patients with serious respiratory illness and their families (9, 10).

In addition to potentially improving access, primary palliative care has several other potential benefits as it can leverage longitudinal therapeutic patient–clinician relationships and trust, use a continuum of care approach gradually integrating palliative with usual medical care over time, and normalize early components of ACP such as identifying surrogate medical decision-makers (29–32). Therefore, all pulmonary–critical care clinicians should screen patients for symptoms and palliative care needs and know how to integrate core aspects of palliative care within usual care for patients with serious respiratory illness (11). Inherent in this model are established best practices facilitated by comprehensive palliative care education and requisite training that includes, but is not limited to, serious illness communication and comprehensive symptom assessment and management (33–35). Clinician competencies should be commensurate with the degree of specialization and relevant to the populations served (e.g., patients with COPD or ILD). To date, the benefits of a primary palliative care model for those with serious respiratory illness have not been well studied, with limited evaluation of nurse practitioners in oncology clinics (36, 37). Other key unanswered questions regarding primary palliative care models include the following: 1) discerning strategies for early identification of patients who may benefit from palliative care; 2) identifying potential referral triggers for secondary palliative care when needs exceed that of a frontline pulmonary–critical care clinician (Figure 4); and 3) developing the most effective ways to teach pulmonary–critical care clinicians and trainees (e.g., fellows and respiratory therapy students) through continuing palliative care education, comanagement delivery models (particularly for more complex needs), and health system-level policies to support implementation. Sources for palliative care education, training, and other resources are included in Table 3.

The coronavirus disease (COVID-19) pandemic brought unprecedented changes to the delivery of healthcare, including the rapid implementation of telehealth and virtual technology (38). The potential value of telehealth in delivering palliative care is difficult to overlook, especially in partnership

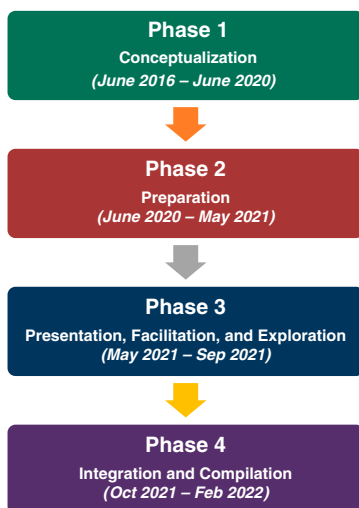
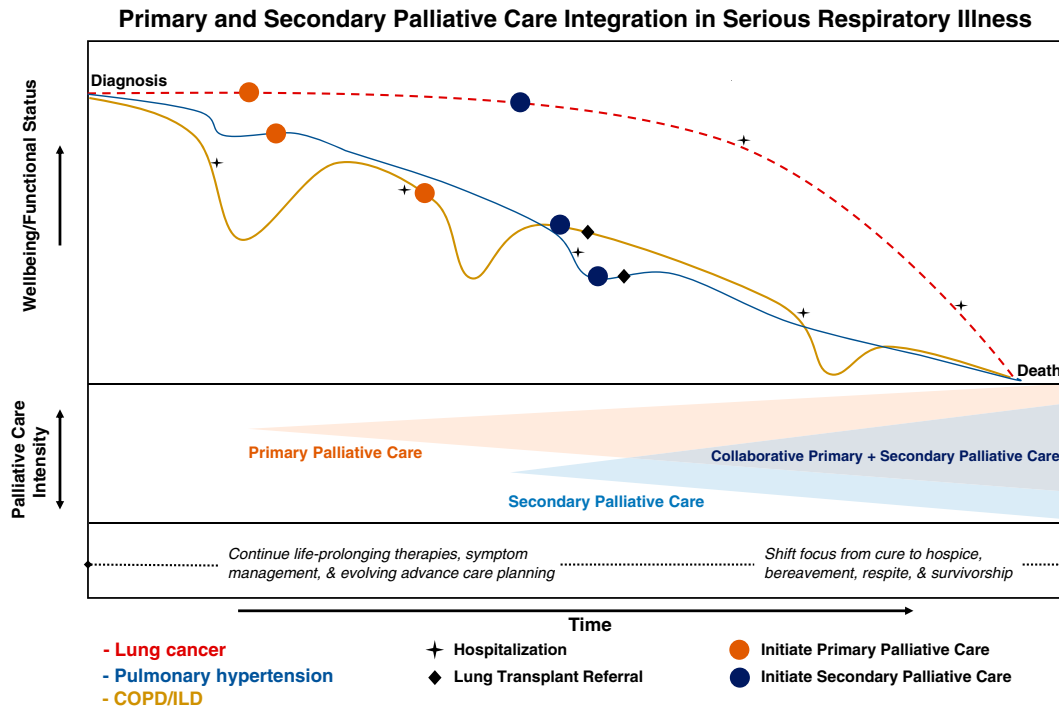


Figure 2. Multiphase iterative development of the policy statement. This figure illustrates the four phases of iterative development of the policy statement over multiple years through conceptualization (phase 1), preparation (phase 2), presentation, facilitation, and exploration (phase 3), and integration and compilation (phase 4).



Secondary palliative care is sometimes referred to as specialist palliative care.

Figure 3. Primary and secondary palliative care integration in serious respiratory illness. This figure has three panels. In the top panel, the x-axis denotes patient wellbeing and function, and the y-axis denotes time. The top panel illustrates the hypothetical integration of palliative care across illness trajectories of lung cancer (red dashed line), pulmonary hypertension (blue line), and chronic obstructive pulmonary disease/interstitial lung disease (COPD/ILD; gold line), each punctuated by declines in wellbeing at hospitalizations (stars) and potential lung transplant referral (diamonds). The integration of primary palliative care (orange circles) starts early (see Figure 4 for triggers), and the integration of secondary palliative care (blue circles) is added later, but well before the end of life. In the middle panel, the x-axis denotes palliative care intensity, and the y-axis denotes time. Primary palliative care increases in intensity after initiation (expanding orange triangle) as serious respiratory illness worsens, and secondary palliative care starts later and also increases in intensity but layers on top of secondary palliative care (expanding blue triangle). Through ongoing comanagement, a period of collaborative primary and secondary palliative care (overlapping triangles) should occur as illness severity worsens through the end of life. The bottom panel illustrates how palliative care may evolve across a continuum of serious respiratory illness. When illness is less severe, palliative care occurs concurrent with illness-directed therapies and then shifts focus from cure to end-of-life care (e.g., hospice and bereavement support) near and after death. This figure is adapted by permission from Iyer, AF. The Role of Palliative Care in COPD. *Chest* 2022;161: 1250–1262.

with community-based programs. Telehealth may be particularly advantageous in delivering palliative care to those with serious respiratory illness who may have mobility and transportation barriers and those in remote or resource-limited settings (39, 40). There also are legitimate concerns that technology could worsen inequities (41), and the unintended consequences of remote delivery of palliative care for patients with serious respiratory illness are largely unexplored (42). However, models of telehealth primary palliative care delivered in a collaborative fashion with rural, community nursing teams have been successful (43, 44).

II. Comprehensive Symptom Assessment and Management

Measurement is a fundamental principle of illness management. As Edwards Deming noted, “if you can’t measure it, you can’t improve it”. Interprofessional approaches to symptom assessment and management in serious respiratory illnesses offer opportunities for more effective collaboration and coordination of care across disciplines. This is vital as patients with serious respiratory illness can experience significant symptom burden (45–48); however, symptoms often go undetected by clinicians (49–51) or are underreported by patients during routine clinical

encounters (52). Detailed patient-reported symptom assessments can increase rates of symptom discussions between patients and clinicians (53–55), intensify symptom management by clinicians (53, 56, 57), and improve patient symptom control and health outcomes such as QOL (58–60). Comprehensive, individualized symptom assessments help determine the true impact of an illness on a patient’s life, including limitations of activity, psychological manifestations of disease, missed work and economic hardships, and effects on family routines and overall wellbeing, among others. Accurate symptom assessment is also essential for consideration of additional

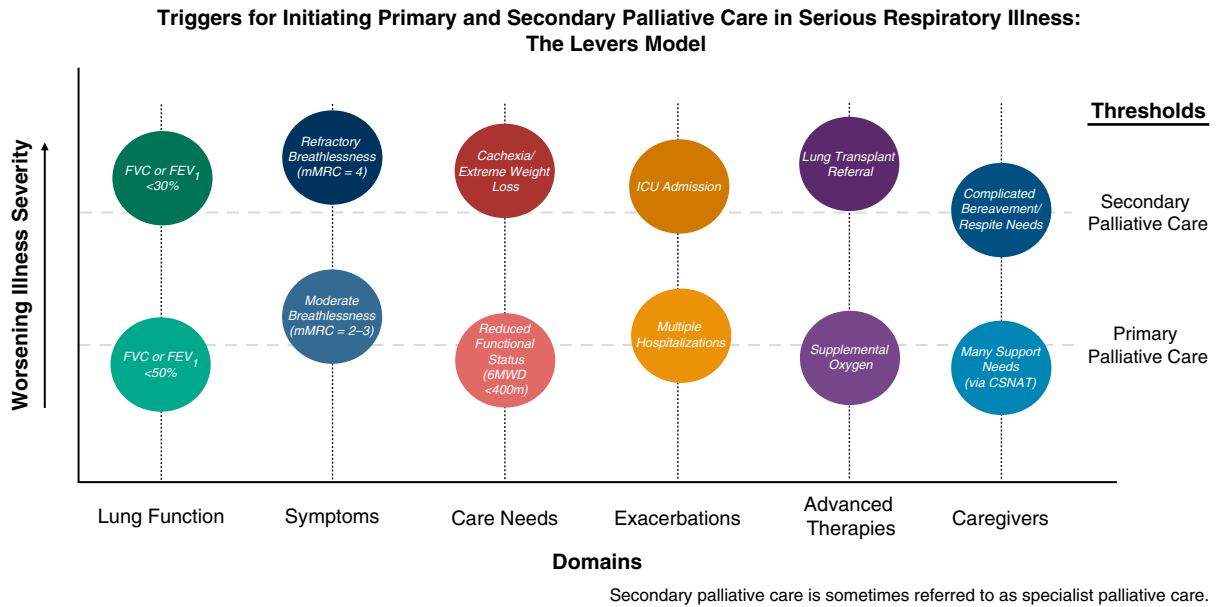


Figure 4. Triggers for initiating primary and secondary palliative care in serious respiratory illness: the levers model. Hypothetical triggers for primary and secondary palliative care occur across multiple domains: lung function, symptoms, care needs, exacerbations, advanced therapies, and caregivers. The x-axis denotes worsening illness severity, whereas the y-axis denotes multiple domains, each with a circle functioning as a lever that can move up or down, crossing a threshold for primary or secondary palliative care, illustrated by the dashed lines. Any one or multiple domains can cross a trigger threshold for consideration for primary or secondary palliative care initiation. For example, a person can trigger consideration for primary palliative care when their FEV₁ drops below 50% predicted (lung function domain). Also, a person can trigger consideration for secondary palliative care when their breathlessness becomes severe on the Modified Medical Research Council (mMRC) (symptoms domain). 6MWD = 6-minute-walk distance; CSNAT = carer support needs assessment tool. This figure is adapted by permission from Iyer, AF. The Role of Palliative Care in COPD. *Chest* 2022;161: 1250–1262.

therapeutic approaches and prognostication (61–66).

Individualized, evidence-based symptom assessments should occur routinely to assess change and identify new symptoms. Important symptoms to assess among patients with serious respiratory illness include chronic dyspnea or breathlessness, episodes of dyspnea crisis, cough, pain, fatigue, sleep disturbances/insomnia, psychological and spiritual distress or suffering (e.g., anxiety, panic attacks, depression, existential angst, and sense of meaning), and weight loss/anorexia (47, 67–69) (Table 4). These symptoms may present in isolation or as symptom clusters, which are a nonrandom distribution of symptoms suggesting a common etiology or pathway (131–134). Pain–insomnia–fatigue and dyspnea–cough are commonly recognized clusters (135). In addition, social assessments should be conducted periodically, including patient relationships with their partners or caregivers with attention to caregiver support and strain, as there is a significant correlation between patient and caregiver health status (20, 25, 136–138).

Central to symptom management in several serious respiratory illnesses is pulmonary rehabilitation; for people with COPD and ILD, it is an effective intervention for breathlessness, fatigue, and emotional symptoms (139, 140). This and other nonpharmacologic treatment options may complement disease-directed pharmacologic therapies such as inhalers, nebulizers, mucus clearance medications, immunosuppressants, and antifibrotics, among others (66). Although not exhaustive, some of the more common pharmacologic and nonpharmacologic therapies are listed (Table 5). Low-dose opioids are the mainstay of refractory breathlessness treatment in patients with advanced cancer; however, they are often underused in those with serious respiratory illness because of concerns they may reduce respiratory drive and hasten death. However, the potential for serious opioid-related side effects may be overstated, as a recent trial found that low-dose oral sustained-release morphine improved health status in patients with COPD without causing hypercapnia or other serious adverse effects (163). Additional advanced palliative therapies may be considered in select patients if

the potential benefits outweigh the risks (e.g., endobronchial valves in COPD, palliative radiation, or stents in lung cancer).

Clinicians should encourage self-care maintenance among patients with serious respiratory illness as it is an essential treatment adjunct that can improve QOL, reduce respiratory-related hospital admissions, and decrease dyspnea (164). According to the middle-range theory of self-care in chronic illness, interventions may focus on one of three related dimensions: self-care maintenance, monitoring, and management (165). Self-management of breathlessness among patients with serious respiratory illness should be a focus as chronic breathlessness causes significant panic, distress, and desperation that significantly limits daily activities and social life (166). Among patients with serious respiratory illness, components of self-care interventions include recognition and treatment of exacerbations, physical activity and exercise behaviors, and education and tools to self-manage symptoms such as breathlessness (164, 167). For instance, clinicians can help patients and caregivers in

Table 3. Sources for Palliative Care Education, Training, and Other Resources

Organization	Content Focus	Website
American Academy of Hospice and Palliative Medicine	Professional organization for physicians specializing in hospice and palliative medicine, nurses, and other healthcare professionals. Provides education and advocacy.	http://aahpm.org/education/overview
American Thoracic Society	Medical society dedicated to accelerating the advancement of global respiratory health through multidisciplinary collaboration, education, and advocacy.	www.thoracic.org
California State University Shiley Haynes Institute for Palliative Care	Advance care planning and palliative care education courses for health professionals and organizations looking to develop their teams.	www.csupalliativecare.org
Cambia Palliative Care Center of Excellence at the University of Washington	Provides palliative care education and training for clinicians and conducts research and quality improvement projects to promote innovation in delivering value-based, patient-centered care to diverse populations across the lifespan.	https://cpcce.uw.edu/
Center to Advance Palliative Care	Provides healthcare professionals and organizations with the training, tools, and technical assistance necessary to provide quality health care for people living with a serious illness.	www.capc.org
End-of-Life Nursing Education Consortium	National and international education initiative to improve palliative care through training of nurses and other healthcare providers.	www.aacnursing.org/ELNEC
Fast Facts	Provide concise, practical, peer-reviewed, and evidence-based summaries on key palliative care topics important to clinicians and trainees caring for patients facing serious illness.	https://www.mypcnow.org/fast-facts/
Get Palliative Care	Consumer-facing palliative care videos and information.	www.getpalliativecare.org
Harvard Medical School Center for Palliative Care	Provides palliative care education for physicians, nurses, social workers, pharmacists, and other healthcare professionals.	https://pallcare.hms.harvard.edu/
Hospice and Palliative Nurses Association (HPNA)	National professional organization that represents the specialty of palliative nursing, which includes hospice and palliative nurses. HPNA supports the profession through education programs, research initiatives, and advocacy.	www.advancingexpertcare.org/HPNA
Prepare for your care	Patient-centered tools to help make medical decision-making easier for people and caregivers.	www.prepareforyourcare.org
Respecting Choices	Guides organizations and communities to integrate and disseminate evidence-based best practices that ensure individual preferences and decisions for health care are known and honored.	https://respectingchoices.org/
Social Work Hospice & Palliative Care Network	Advocacy and professional development through education, evidence-informed best practice, social work-informed research, and specialty certification.	https://www.swhpn.org
VitalTalk	Evidence-based communication training for physicians and advanced practice providers working with seriously ill patients and their families.	https://www.vitaltalk.org

developing an action plan for breathlessness with instructions for worsening symptoms, including crises. These action plans may include home spirometry monitoring, starting an oral corticosteroid, temporarily limiting strenuous activities, avoiding tobacco products (if applicable), practicing breathing-relaxation training, receiving massage therapy, or notifying their clinicians (168, 169). Patients and their caregivers can become adept at preventing, controlling, and

managing the physical, psychological, and social consequences of respiratory illness, and clinicians should encourage self-care management activities while acknowledging their potential limitations.

III. Advance Care Planning and Goals of Care Discussions

ACP is a process that supports persons “at any age or stage of health in understanding and sharing their personal values, life goals,

and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness” (7). Goals of care (GOC) discussions may help ensure that care is consistent with patient preferences, and these discussions can be framed around specific medical interventions (e.g., intubation and mechanical ventilation). However, this

Table 4. Symptom Assessment Instruments

Symptom	Tool	Brief Description	Validation
Health-related quality of life	Chronic Respiratory Questionnaire	25 items rated on 7-point Likert scale. Focused on the last 2 wk. Available in interviewer or self-administered versions with optional dyspnea domain. Licensed.	Originally designed and validated for patients with COPD (70). Patients with COPD before and after pulmonary rehabilitation (71). Patients with ILD before and after pulmonary rehabilitation (72). Patients with COPD and ILD (73).
	King's Brief Interstitial Lung Disease	15 items measuring three domains (breathlessness and activities, chest symptoms, and psychological). Focused on last 2 wk, one question with no time period. Licensed.	Designed and validated for patients with ILD (74). Updated MCID in patients with ILD (75).
	St George's Respiratory Questionnaire	50 items measuring symptoms impacts. Focus on 1, 3, or 12-mo recall. Free to use for noncommercial entities.	Patients with COPD before and after pulmonary rehabilitation (71). Patients with ILD before and after pulmonary rehabilitation (72).
	Short-form 36-item Survey	36 items rated on Likert scales measuring 8 concepts, broadly categorized into mental and physical component scores. Focus on the past 4 wk and the current. Free to use.	Patients with ILD before and after pulmonary rehab (72). Male patients with COPD (76). Partially responsive to pulmonary rehabilitation in male and female patients with COPD (77).
	Clinical COPD Questionnaire	10 items rated on 7-point Likert scale. Focuses on the past week. Free to use.	Patients with COPD before and after pulmonary rehabilitation (71).
	Euro-QOL 5D	6 questions, allow for monitoring of changes in self-reported health status through time or in response to treatment. Free to use for noncommercial entities.	Patients with COPD (78).
	Living with Idiopathic Fibrosis	44-item questionnaire specific for patients living with IPF. Licensed.	Patients with IPF (79).
	COPD Assessment Test	8 items rated on a 0–5 scale of severity. Self-administered. Licensed.	Developed and validated in patients with COPD (80). Responsive to pulmonary rehabilitation in patients with COPD (81). Validated in patients with ILD (82).
	Breathlessness	Modified Medical Research Council Dyspnea Scale	Single item assessing breathlessness severity on a scale of 0-4. Free to use.
Visual Analog Dyspnea Scale		A single-item rating of breathlessness along a visual line. Has the same limitations as the NRS—single domains measured only. Free to use.	Validated in patients with COPD and asthma against the Borg exertion scale (86). Validation in patients with ILD, including MCID (87).
Numeric Rating Scale		A single-item rating of 0 to 10. Modeled from the NRS for pain. Only measures one domain but can be used for multiple separate symptom questions (e.g., breathlessness intensity and breathlessness unpleasantness). Free to use.	Validated in patients with COPD with high correlation against VADS (88). Patients with COPD and ILD (73).
Dyspnea-12		12 items rated on a scale of 0 to 3 severity. Focuses on “these days”. Free to use.	Developed and validated in patients with COPD, ILD, and chronic heart failure (89). Validated in patients with ILD (90).

(Continued)

Table 4. (Continued)

Symptom	Tool	Brief Description	Validation
Cough	Respiratory Distress Observation Scale	8 items rated on a scale of 0 to 2 severity assessing the intensity and distress of dyspnea among patients unable to self-report. Free to use.	Developed and validated in patients with a pulmonary or cardiovascular disorder and postoperative pain and healthy volunteers (91, 92).
	Leicester Cough Questionnaire	19 items rated on 7-point Likert scale across three domains (physical, psychological, and social), measuring the impact of cough. Self-administered. Free to use.	Designed and validated for chronic cough patients (93). Validated for patients with COPD (94). Validation in patients with ILD (85).
	Cough Symptom Score	2 items rated on a 0–5 scale assessing cough symptoms during daytime and nighttime. No information on copyright.	Design and validation in chronic cough patients (95).
Pain	Cough and Sputum Assessment Questionnaire	20 items measuring 4 domains (cough and sputum symptoms and respective impact). Focused on past 7 d. Self-administered. Licensed.	Development and validation in COPD and bronchitis (96). Responsive to exacerbations in COPD (97). Usage in ILD (98).
	Pain Sensitivity Questionnaire	17 items rated from 0 to 10. Self-administered No information on copyright.	Review of validation in COPD (99).
	Geriatric Pain Measure	24 items scored as yes/no or on a scale of 0–10. Measures multiple dimensions of pain and can be self-administered. Free to use.	Review of validation in COPD (99).
	Brief Pain Inventory	Short form consists of 9 items. Self-administered. Measures average, least, and worse pain intensity. Free to use.	Validation in patients with ILD (100). Validation in COPD (101). Validation in COPD during exacerbations (102).
Fatigue	Short-form McGill Pain Questionnaire	Short form consists of 2 subscales, 11 sensory items, and 4 affective. Rated on a scale of 0–3. Licensed.	Validation in patients with ILD (100). Validation in COPD during exacerbations (102).
	Functional Assessment of Chronic Illness Therapy scale for fatigue	Short version consists of 13 items modified for COPD. Free to use for noncommercial entities.	Development and validation of COPD version (103).
	Fatigue Severity Scale	9 items rated on 7-point Likert scale. Free to use for noncommercial entities.	Validated in COPD (104). Before and after pulmonary rehab in general advanced respiratory illness (105).
Sleep	Manchester COPD-Fatigue Scale	27 items measuring three dimensions (physical, cognitive, and psychosocial). No information on copyright.	Developed and validated in COPD (106).
	Pittsburgh Sleep Quality Index	10 items measuring 7 subscores, self-administered. Focused on last month. Free to use on request.	Validation in COPD against SGRQ QOL score (107). Validation in COPD (108). Moderate correlation with CAT score in COPD (109). Associated with poor sleep quality in ILD (110).
	Berlin Questionnaire	10 items measuring three categories. Free to use on request.	Validation in COPD against SGRQ QOL score (107). Did NOT predict obstructive sleep apnea in patients with COPD (111) or ILD (112).
	Epworth Sleepiness Scale	8 items rated on 0–3 scale, self-administered. Licensed.	Validation in COPD against SGRQ QOL score (107). Did NOT predict obstructive sleep apnea in patients with COPD (111). Associated with poor sleep quality in ILD (110).

(Continued)

Table 4. (Continued)

Symptom	Tool	Brief Description	Validation
Psychological wellbeing	Hospital and Anxiety Depression Scale	14 items rated on a 4-point scale, 7 assess depression, and 7 assess anxiety. Licensed.	Validated in COPD, including MCID (113). Correlation between dyspnea and comorbidities in patients with ILD (114). Usage in COPD (115, 116).
	Patient Health Questionnaire-9	9 items rated on the Likert Scale, assesses depression severity. Free to use.	
	Geriatric Depression Scale	Long-form is 30 items. Short form consists of 15 items measured as yes/no responses. Free to use.	Correlated with life event stress in patients with COPD (117). Responsive to pulmonary rehab in ILD (118).
	Beck Depression Inventory II	21 items rated on a 4-point scale of severity, focuses on 1–2 weeks. Self-administered. Licensed.	Validated in patients with COPD when question 21 was excluded (119). Not responsive to antifibrotic treatment in ILD (120). Usage in COPD (121).
Weight loss and anorexia	Malnutrition Universal Screen Tool	3-item assessment combining BMI, unplanned weight loss, and acute illness effect to assess malnutrition risk. Clinician-assessed. Free to use.	
General palliative care needs	Needs at the End of Life Screening Tool	13-item scale adapted for use by family members of patients in the ICU that samples from all eight domains of palliative care quality. No information on copyright.	Original version for use by patients with cancer (122, 123). Version adapted for use by family members of patients in the ICU (124, 125).
	Palliative Care Outcomes Scale/Integrated Palliative Care Outcome Scale	10-item scales; POS and IPOS contain two similar measures, one completed by staff, the other by patients to assess: physical, emotional, psychological, spiritual, and provision of information and support dimensions. Licensed.	Usage in patients with serious respiratory illness (e.g., lung cancer, ILD, and COPD) in diverse settings (25, 126, 127).
	Edmonton Symptom Assessment Scale	9-item scale developed for use in assessing the symptoms of patients receiving palliative care. Free to use.	Usage in COPD (128, 129) and lung cancer (130).

Definition of abbreviations: BMI = body mass index; CAT = COPD assessment test; COPD = chronic obstructive pulmonary disease; ILD = interstitial lung disease; IPF = idiopathic fibrosis; IPOS = integrated palliative care outcome scale; MCID = minimally clinical important difference; NRS = Numeric Rating Scale; POS = palliative care outcome scale; SGRQ QOL = St. George’s Respiratory Questionnaire quality of life; VADS = visual analog dyspnea scale.

committee considered a broader definition of GOC discussions as an important component of the ACP process in developing a better understanding of patient values and preferences and does not distinguish these as separate constructs. The ethical principle of respect for patient autonomy underpins the ACP process and autonomous decisions as those that are made intentionally and with substantial understanding and freedom from controlling influences (170). ACP positively impacts the quality of end-of-life care (171, 172) and can support patients, surrogates, and clinicians by avoiding crisis-oriented decision-making at the very end of life that may be inconsistent with patient goals and increase the burden and stress for surrogates (173–176). This is particularly relevant for

patients with serious respiratory illness who are at elevated risk of losing the ability to communicate because of unexpected acute deterioration and the need for decision-making after acute respiratory failure (175, 177–180). As a result, pulmonary-critical care clinicians are well-positioned to be leaders in conducting ACP discussions among patients with serious illness and their families.

ACP conversations may include the creation of documents such as advance directives, living wills, assignment of a healthcare proxy, and POLST (Portable/Physician Orders for Life-Sustaining Treatment) that are readily available to the healthcare team. These forms should be reviewed and updated by patients on a regular basis as health or conditions change. However, completion of these documents

without considering the quality of the preceding patient–clinician communication should never be used as a quality metric. In addition, ACP documents have limited ability to address all potential health scenarios; thus, healthcare proxies should be prepared to make substituted judgments (181–184) and, ideally, with patient consent, should be included as active participants in ACP discussions as healthcare decisions can be overwhelming.

ACP consists of structured communication and documentation that are woven into the regular process of care provided to patients and their families and should begin in the early stages of respiratory illness (Figure 5). This early and iterative approach may help to normalize these conversations and is a key recommendation

Table 5. Complementary Pharmacologic and Nonpharmacologic Symptom Management Therapies in Serious Respiratory Illness*

Symptom	Nonpharmacologic	Pharmacologic
Dyspnea or breathlessness	Acupuncture/acupressure/massage, noninvasive positive pressure ventilation, supplemental oxygen therapy, breathing or relaxation techniques (e.g., pursed lip breathing, breathing-relaxation training), fan therapy (141–146)	Opioids (141–144)
Cough	Chest physiotherapy, speech therapy, breathing exercises (147–149)	Opioids, neuromodulators, cromoglicic acid/sodium cromoglycate, central antitussive agents, GABA analogs (150–153)
Pain	Acupuncture/acupressure/massage, music therapy, surgical options (e.g., surgical debulking and vertebroplasty) (154–157)	Opioids, antidepressants, anticonvulsants, muscle relaxants, anxiolytics, corticosteroids, topical analgesics (158–160)
Psychological distress (e.g., anxiety and depression)	Cognitive-behavioral therapy, counseling and other support, coping skills training, mindfulness-based stress reduction, music therapy (161, 162)	SSRI or tricyclic antidepressants, anxiolytics, ketamine, methylphenidate (161, 162)

Definition of abbreviations: GABA = γ -aminobutyric acid; SSRI = selective serotonin reuptake inhibitor.

*These approaches may be considered complementary to evidence-based and disease-directed pharmacologic and nonpharmacologic therapies (e.g., inhalers, nebulizers, mucus clearance and immunosuppressive medications, antifibrotics, and pulmonary rehabilitation, among others).

of the 2014 Institute of Medicine, Dying in America Report (185). Early initiation of ACP also is consistent with a recent consensus definition that states that ACP should support persons at any age or stage of health (7). In addition, early ACP can strengthen patient–clinician relationships and provides an opportunity to introduce the concept of palliative care (186–188). Respecting Choices is one successful model intended to normalize ACP communication using a stepped approach in which the early

stages of the process may only focus on asking patients to identify a medical decision-making surrogate (189).

Improving uptake of ACP is not without significant challenges (190–192), including the need for clinicians to acquire specialized knowledge and skills through feedback from ACP facilitators and/or serious illness communication experts, as well as ongoing opportunities to practice these skills. Unfortunately, a lack of knowledge or formal training in ACP persists

among pulmonary–critical care clinicians (193–195) despite evidence that training and education have positive effects on clinician knowledge, attitude, and skills in conducting ACP (196). For these reasons, completion of serious illness communication and ACP training should be required of all pulmonary–critical care clinicians and trainees as a core competency. This training has been endorsed by representatives of the ATS, the American College of Chest Physicians, the Society of Critical Care

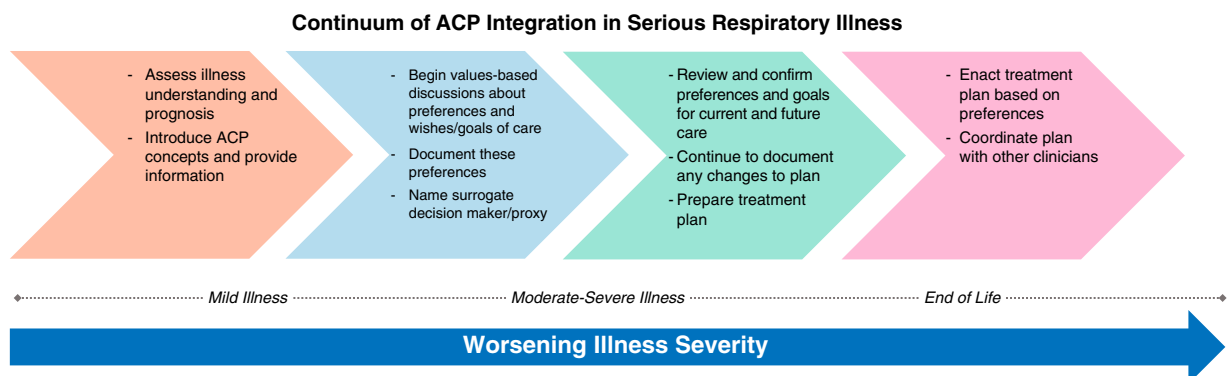


Figure 5. Continuum of advance care planning integration in serious respiratory illness. The continuum of ACP in serious respiratory illness is a longitudinal process of communication that begins soon after illness diagnosis (stage 1: first arrow) and increases in intensity on the basis of patient illness trajectory (stages 2–4). This process should be free of coercion, and clinicians should be alert to signs of patient distress or discomfort. Patient-designated surrogates or healthcare proxies should be included across all stages with patient permission. ACP = advance care planning.

Medicine, and the Association of Pulmonary and Critical Care Medicine Program Directors as Entrustable Professional Activities (197).

Despite the potential importance of ACP, it is worth noting emerging concerns about the limited evidence supporting the effectiveness of ACP in achieving goal-concordant care or in improving family member perceptions of quality of care (190, 198). These findings may be because of the inability to plan for or envision the myriad of potential health situations that may arise over the course of an illness and the inability to foresee the emotional and psychological challenges that can occur during in-the-moment decision-making (190, 198). Some dissensus existed within the committee regarding the importance and future role of ACP in serious respiratory illness, given concerns about its effectiveness and the focus within the ACP literature on the creation of documents (e.g., advance directives). These concerns reinforce the committee's consensus recommendations regarding ACP for 1) early identification of healthcare proxies to enable them to better prepare for

in-the-moment decision-making using substituted judgment; and 2) a shift in focus away from document completion as the goal of ACP to ensuring high-quality serious illness communication occurs instead.

IV. Caregiver Support

Informal caregivers or caregivers (e.g., family members, partners, and friends in unpaid roles) provide essential support to patients living with serious respiratory illness (199) which can be rewarding and provide caregivers a sense of accomplishment (200). Caregivers are alternatively referred to as “carers”, “care partners”, or sometimes “supporters”. The caring role can also have negative impacts on the caregiver(s), and both patients and caregivers report a range of unmet support needs throughout the illness course (199, 201, 202). These can include a need for disease education, learning how to use respiratory equipment (e.g., oxygen delivery devices), information about financial assistance, and help navigating the healthcare system. Supporting the caregiver helps to sustain caregiving, thereby supporting the patient (See Box 1).

The first step in supporting caregivers is identifying them (199). Many patients and caregivers do not recognize labels such as “caregiver” or “carer” and can confuse these labels with formal (i.e., paid) caregivers. Caregivers see themselves in relational terms (e.g., spouse or partner, child, or friend), and patients may not accept the idea of being “cared for” and so reject the label. It is, therefore, better to reframe identifying questions to patients as “who gives you help and support at home?” (199, 201). Clinicians can thus be instrumental in helping caregivers access crucial support services and financial benefits. Clinicians should also acknowledge that there can be multiple caregivers performing various roles, and these caregivers may be geographically distant and can change throughout the lifespan of the patient. Therefore, ongoing identification of caregivers should be revisited during follow-up clinical encounters.

Condition-specific needs related to caregivers of patients with serious respiratory illness exist (201). For instance, patients being evaluated for lung transplantation and those on the transplant waitlist are required

Box 1. A Patient and Caregiver Perspective

Patient Voice:

Lung disease is awful. When you receive the bad news that you have a serious or terminal lung disease, you freeze, and you hear nothing else. Then you hope that your clinician or team of clinicians can help guide you and your family through the process of making tough treatment decisions. Decisions that reflect “who you are” and “how you want to live”. Sadly, this happens all too seldom. Even clinicians with communication training can get it wrong when the conversation begins with an advance directive checklist and questions about end-of-life decisions; you turn off, and you lose trust. Consequently, you miss out on a lot of support that can help down the road. Clinicians need to first understand who a patient is as a person, what we are experiencing, and what we want and need now and in the future before explaining how palliative care services can benefit us and our loved ones. Invite us and our caregivers to be active participants in the team to set the ground rules for future interactions. We tend to be receptive to receiving support if we believe we are being taken seriously and respected, which gains trust. Once trust is established, it makes it much easier to introduce palliative care and end-of-life issues. It is critical that all clinicians are educated to communicate with patients and our families using standard approaches, and hopefully, this can ensure we receive high-quality palliative care. It doesn't matter which member of the team introduces palliative care; getting help for the patient and caregiver is the goal.

Caregiver Voice:

We were told by my husband's doctor we had 1–2 years when he was diagnosed with pulmonary fibrosis: we got 21 months and made every minute count. Every day we said aloud, “I love you”. Although we had family and friends to help, the majority of care fell on me as a spouse. Each day was a regimented, at times exhausting, schedule. No one discussed palliative care with us. From life's experiences and a little medical knowledge, I was able to ask the right questions to know what he really wanted at life's end. Visiting nurses started only 3 months before he passed away; hospice entered 10 days before his death. Both assured me I had been correctly caring for him all those months by myself. What a relief to my heart. Our journey would have been so much easier if palliative care was offered as soon as we were told his illness was terminal. Caregivers (spouses, children, family members, and friends) need to be included and acknowledged at every medical visit, including when palliative care is introduced. We need to know what the palliative care team can offer us and what they can't provide (like care during a crisis in the middle of the night). We need to be asked about our loved ones—we see and know things clinicians don't. Importantly, we need to be offered support and services for our own needs, too, including a support network.

Table 6. Resources for Caregivers

Source	Websites
American Thoracic Society	Palliative Care for People with Respiratory Disease or Critical Illness https://www.thoracic.org/patients/patient-resources/fact-sheets-az.php - Palliative Care 2021: Palliative Care for People with Respiratory Disease or Critical Illness - Code Status 2022: Making Decisions about Serious Illness: What is Code Status? Making Decisions about Serious Illness: What is Code Status? www.thoracic.org/patients/making-decisions
Pulmonary Fibrosis Foundation	https://www.pulmonaryfibrosis.org/patients-caregivers/medical-and-support-resources/for-the-caregiver
COPD Foundation	https://www.copdfoundation.org/Learn-More/I-am-a-Caregiver/FAQ-for-Caregivers.aspx
GO2 Lung Cancer Foundation Help and advice for caregivers supporting someone with breathlessness American Lung Association:	https://go2foundation.org/resources-and-support/support-groups/ https://supporting-breathlessness.org.uk/ https://www.lung.org/lung-health-diseases/lung-disease-lookup/lung-cancer/family-and-friends/taking-care-of-yourself https://www.lung.org/lung-health-diseases/lung-disease-lookup/pulmonary-fibrosis/family-and-friends/find-caregiver-communities
Cystic Fibrosis Foundation Action for Pulmonary Fibrosis British Lung Foundation Marie Curie: Managing Breathlessness	https://www.cff.org/coping-while-caring-someone-cystic-fibrosis https://www.actionpf.org/information-and-support/carer-family-friends https://www.blf.org.uk/support-for-you/carers https://www.mariecurie.org.uk/help/support/publications/living-with-terminal-illness/managing-breathlessness
Society of Critical Care Medicine	https://www.sccm.org/MyICUCare/THRIVE

Definition of abbreviation: COPD = chronic obstructive pulmonary disease.

to have an identified caregiver present at transplant evaluation and through posttransplant. Incorporating an assessment of caregiver needs early in the lung transplant process may be useful in identifying caregivers who need more support from the transplant team and/or a palliative care consult in the posttransplant period (202). Respiratory illnesses also often require technical equipment (e.g., mechanical ventilator and oxygen delivery device), and palliative care may include helping caregivers adjust to being responsible for this equipment (203, 204).

Caregiver support is everyone’s responsibility. The caregiver should be acknowledged by the clinician and, at a minimum, asked how he/she is doing (directly or via the patient if the caregiver is not present). Evidence-based approaches (e.g., CSNAT-1 [Carer Support Needs Assessment Tool Intervention]) (205, 206) allow caregiver support needs to be comprehensively identified and addressed. Exploring caregiver needs jointly with the patient can raise patient awareness of caregiver needs, but opportunities to talk about

needs separately from the patient should also be provided. As needs change, conversations should be revisited along the illness trajectory, including into bereavement. It can sometimes take a clinician to identify caregiver needs, as caregivers themselves may not recognize them (i.e., being overprotective of the patient). Timely/early provision of information on support options can reinforce the idea that caregivers also need to care for themselves.

Clinicians should take a person-centered, caregiver-led approach to meeting needs and identifying solutions. Conversations around support needs are enough to make caregivers believe they are more supported. Other times provision of information or education, resource signposting (Table 6) or referral is required (e.g., support groups, advocacy organizations, psychological support, or wellbeing services). Caregivers should be kept informed and involved in decision-making (with the permission of the patient). Technology can facilitate this for geographically distant caregivers (e.g., telephone, video

conferencing, or Caring Bridge [207]), although technical skills and preferential barriers may exist.

V. Health Disparities

Given the evidence base for the benefits of palliative care in serious respiratory illness, it is imperative that palliative care services are equitably distributed, of similar quality, and meet the needs of all eligible people. Access to palliative care is a fundamental right regardless of citizenship status, sex, race/ethnicity, houselessness, LGBTQIA+ status, rurality of home residence, or insurance status. However, evidence demonstrates that social, cultural, and economic factors continue to limit access (208–210). Striking disparities in access exist among socially disadvantaged populations (211) as well as rural communities (4, 212). Inequitable access may be worse internationally, especially in low- and middle-income countries, as only 14% of the global population has access to the highest degree of palliative care, which outside of the United States and Canada is concentrated in Western Europe and Australia (5).
 Synonymous with inadequate access to

Table 7. Communication Considerations and Strategies among Disadvantaged Groups

Theme	Rationale	Implementation
Attitudes toward ACP documentation	Patients who belong to some ethnic groups are less likely to engage in ACP because of cultural or religious beliefs or distrust of the medical system as a result of historical mistreatment of certain communities (240–242).	Offer referral to a clinician of a similar ethnic/cultural background as some patients may be more comfortable because of historical or structural discrimination. Patients and families may also be encouraged to derive support from their individual systems of faith or consult their faith leaders for additional guidance. Clinicians can use electronic medical record templates to document detailed ACP discussions (allowing patients to edit content through secured portals); printed copies can be shared with patients.
Family support in decision-making	There are important differences in cultural orientation toward individualism or communalism as values of how individuals express their autonomy (243). Therefore, clinicians may encounter meaningful differences in family involvement in serious illness decision-making by race and ethnicity.	If patients are amenable, clinicians should recommend family or informal caregiver inclusion in serious illness discussions. Clinicians should inquire how and to what extent patients want their families involved.
Lower health literacy	Clarify potential discordant understanding of the diagnosis or clinical situation during discussions. Discordance affects patient and family concerns and understanding of their needs at all stages of serious respiratory illness.	At the outset of all discussions, ask patients and families to describe their understanding of the situation, diagnosis, or trajectory of illness.
Non-English speakers	Tone of voice, facial expressions, body language and gestures, and eye contact are all forms of nonverbal communication that are interpreted by patients and families (244–246). Ensure patient and family understanding when interpreters are used (247, 248).	Be cognizant of nonverbal communication. Unless you are a native speaker, using translators as professionally trained interpreters can be effective cultural mediators (249).
Refugees, immigrants, and undocumented citizens	On the basis of responses, clinicians may be able to provide patients and families access to local or institutional resources to address needs.	Ask questions about patient and family backgrounds that may inform decision-making (e.g., historical and political context of their lives, place of birth, experiences with poverty, experience with discrimination, and degree of integration within their ethnic community).
Prognostication	Some cultures believe that discussing death hastens the process and/or have taboos against talking about death (243, 250–252).	Refrain from making assumptions about the degree of information patients and families want. Ask patients and families directly who they want to receive information, how they want it conveyed, and how much information they want to know. Given the potential for prognostic uncertainty at the end of life, providing categorical time estimates such as “days”, “weeks”, or “months” without specifying a number may facilitate a shared awareness (253, 254).

Definition of abbreviation: ACP = advanced care planning.

palliative care, racial and ethnic disparities in opioid treatment and accessibility for pain exist in many communities (213–220). This is particularly meaningful as respiratory illness disproportionately affects individuals from disadvantaged populations (221), and the lowest socioeconomic groups are up to 14 times more likely to be afflicted than the highest group (222).

Even in similarly-resourced settings, disparities in the quality of palliative care are reported, particularly regarding clinician communication (223–226). Breakdowns in

communication can result in more intense care at the end of life, increased in-hospital deaths, and increased financial burden and complicated bereavement for families (227). Ineffective communication also contributes to reduced knowledge and completion rates of advance care planning among African Americans, Hispanics, and Asians (228–233). Ensuring equitable access to advance care planning among disadvantaged populations is important; however, these efforts should emphasize efforts to determine patient readiness,

avoidance of coercion, and development of a better understanding of cultural beliefs and practices about and attitudes toward end-of-life care choices enabling individualized approaches. Underlying ineffective communication may be a result of a lack of cultural awareness, such as proper language/linguistics regarding end-of-life issues among clinicians, which likely perpetuates the ongoing lack of trust among some groups (234). Both the National Quality Forum and National Consensus Project for Quality Palliative Care identify

Table 8. A Framework for Planning a Palliative Care Response during a Catastrophic Event on the Basis of the U.S. Task Force on Mass Casualty Critical Care Guidelines (258)

Critical elements	Description
Stuff	A medication stockpile (“palliative symptom management kits”) should be created for long-term use by all facilities, paramedics, and other healthcare professionals. Adequate PPE should be available to facilitate safe care delivery.
Staff	Response plans should include all healthcare professionals with palliative care training as well as those who can educate others in palliative care.
Space	Usage of nearby locations or specialized wards may be necessary to ensure a peaceful and quiet environment for dying patients.
Systems	Triage systems and virtual care models can be used to protect clinicians from the risk of infection while also increasing their efficiency.
Sedation	Sedation can offer comfort to patients whose symptoms are not responding to standard comfort medications.
Separation	Patients can use video calling and other technologies to connect with family members to lessen the sense of separation they may experience because of isolation measures. In-person visitation should be considered if all parties are willing to accept risks and appropriate PPE is available.
Communication	Some patients may not want to undergo life-saving measures, so an understanding of patient wishes is critical. It is important to maintain open communication with patients and their families.
Equity	All patients should have access to palliative care, regardless of status as a marginalized group, such as those with disabilities, trauma, or poverty.

Definition of abbreviation: PPE = personal protective equipment.

the provision of culturally sensitive care as one of eight core domains of high-quality palliative care (235). Successful palliative care interventions to reduce disparities have included strategies to enhance cultural awareness among clinicians and improve health literacy among patients (231, 236–239). In addition, efforts to diversify the palliative care workforce, including healthcare professionals, social workers, spiritual care workers, and community health workers, are long overdue and will require innovative solutions. Comprehensive training (e.g., palliative care terminology and communication; active listening; and cultural traditions, awareness, and sensitivity) of pulmonary–critical care clinicians is essential in the provision of primary palliative care. (Table 7)

VI. Mass Casualty Events and Emergency Preparedness

Natural disasters and catastrophic mass casualty events, such as COVID-19 or influenza pandemics, are increasing in frequency and severity, resulting in widespread human, material, economic, and environmental impacts yielding thousands of victims whose needs overwhelm local and regional healthcare systems, personnel, and resources (255). These events generally fall into two categories: 1) “big bang” single incidents with immediate or sudden impact,

such as airplane or train crashes, which yield large numbers of casualties at the outset of the event with few added over time; and 2) “rising tide” incidents that start with few casualties such as pandemics or widespread, ongoing exposures to chemical, biological, and nuclear agents yielding a gradual increase in the number of people affected over time, rising to catastrophic numbers with prolonged impact and necessitating a more prolonged response (256). Such conditions necessitate deploying scarce resources in a manner that is different from usual care, ranging from conventional to contingency to crisis standards of care.

The COVID-19 pandemic has highlighted increasing palliative care needs across healthcare systems (257). As illustrated by the pandemic, crisis palliative care focuses on three domains: 1) management of symptoms; 2) discussion of patient wishes, expectations, and values; and 3) supporting families of those with life-limiting injury or illness (209). At a minimum, palliative care in catastrophic disasters should include aggressive and appropriate treatment of pain and other symptoms and support and comfort for patients, their families, and their clinicians (256–260). Although the primary goal of a coordinated response to a mass casualty event is to maximize the number of lives saved, a comprehensive response should also

seek to minimize the suffering of those who may not survive (256). As healthcare clinicians, there is always something to offer, even at the end of life. A framework for providing palliative care during a catastrophic event is summarized in Table 8.

VII. Research Priorities

Currently, there are numerous challenges to delivering palliative care to the right patient at the right time. In fact, it is unclear who ideally should receive palliative care, from whom it should be delivered, and what exactly the appropriate intervention(s) should be. Patient and caregiver populations for palliative care research studies should be identified on the basis of needs for, and the likelihood of benefit from, palliative care services. Palliative care trigger tools (i.e., tools that indicate the need or suggest the timing of referral) are available for specific patient populations, such as those admitted to an intensive care unit (ICU) (261). However, given that palliative care triggers may not be associated with palliative care needs (125), measurement tools to differentiate patients who could benefit from primary vs secondary palliative care further upstream in the illness trajectory (i.e., in ambulatory settings) would be helpful. Palliative care outcome measures should expand beyond healthcare system/usage outcomes (262, 263) as palliative care services often include

Table 9. Research Priorities

Categories	Examples
Study methodology	
Measurement	Develop and test novel outcome measures (e.g., patient- and family-centered measures); better define populations who should receive palliative care and the timing of initiation of palliative care
Implementation	Determine how best to operationalize interventions among the seriously ill, using novel study designs when appropriate to evaluate, develop, and test implementation outcomes such as acceptability, adoption, penetration, and sustainability
Content areas	
Patient identification tools	Measurement tools and the use of machine learning to differentiate patients who could benefit from various degrees of palliative care (e.g., primary vs. secondary palliative care) along the illness trajectory (i.e., in ambulatory settings)
Delivery models	Primary palliative care; primary plus secondary palliative care integration; multiprovider and nonclinician integration; technology intervention such as leveraging electronic health records and telehealth interventions
Symptom management	Patient and caregiver self-management strategies; studies identifying best practices in pharmaceutical and nonpharmaceutical management of common symptoms in respiratory illnesses (e.g., acute breathlessness, cough, and fatigue)
ACP and decision-making	Improving ACP and “in-the-moment” decision-making; identifying proxies; examining the outcomes of longitudinal goals-of-care discussions
Caregivers	Dyad-targeted palliative care interventions
Disparities	Interventions to increase workforce diversity; interventions tailored to different cultures and languages and rural populations

Definition of abbreviation: ACP = advanced care planning.

complex interventions such as ACP and symptom management (264). Therefore, multiple outcomes (e.g., patient- and family-centered measures) and implementation outcomes like adoption and sustainability and the use of newer study designs such as MOST (multiphase optimization strategy) (265) are needed to examine which specific component(s) of the intervention are effective, including measuring specific impacts proximal to the intervention and potential harms (20). Research is needed to identify when to initiate palliative care to achieve maximal benefit for patients and families for specific chronic respiratory illnesses (e.g., COPD) (48). Effective telehealth-based palliative care delivery models that include sustainable payment models (266) are critical to reaching patients living in rural and/or underserved communities.

Developing and testing primary palliative care training interventions that are practical, scalable, and embedded within existing clinical settings is an additional priority. The critical shortage of palliative care specialists (267) necessitates pulmonary–critical care clinician competency in fundamental palliative care

skills. More work is also needed to develop models with integrated or comanagement of primary and secondary palliative care in ways that are acceptable, sensible, and efficient (268). Application of novel methodologies and study designs are needed to improve the quality of palliative care evidence in pulmonary and critical care medicine. Examples include quasi-experimental/natural experiments, adaptive designs, hybrid and pragmatic trials, and mixed methods research. Pulmonary palliative care interventions that have been conducted in ICU settings can guide this work; however, further research is urgently needed for seriously ill patients and their caregivers managed in pulmonary outpatient clinics. Lastly, it is critical to include people of color, non-English speakers, and members of rural communities in future studies to ensure a better understanding of their unique palliative care needs (269). Expanding funding for the cultural and linguistic adaptation of effective palliative care interventions to diverse populations offers a high-value opportunity to broaden the reach of palliative care.

The “culture problem” of integrating palliative care into pulmonary and critical

care medicine is a challenge that is not unique to the field. Despite recommendations from professional societies to offer palliative care to patients with advanced cancer, the adoption of palliative care is variable depending on the service and setting (22, 270). Therefore, trials are needed to test the effectiveness of efficacious interventions with primary aims focusing on the outcomes of implementation science, such as clinician adoption of the intervention and sustainability in different practice settings. A clearer framework could help the field guide and successfully implement palliative care while enhancing its scalability. Palliative care interventions in the ICU and pulmonary outpatient settings appear promising, but more research is needed to understand the full range of patient, family, and healthcare system impacts (271).

Technological advancements, including the leveraging of electronic health record systems for useful clinical tasks and the use of methods such as artificial intelligence and machine learning, are likely to accelerate the conduct of future clinical research. Examples include patient identification for study

criteria and outcomes collection. Technology in the form of telehealth can be used to support clinician education, patient self-management, and improved care delivery and disparities. A number of self-directed mobile app-based interventions targeting psychological distress and physical symptoms are also available (272–274). Lastly, researchers from around the globe can meet and collaborate without traveling by using available technology to access data and conduct collaborative research to accelerate innovation.

Other important research priorities include characterizing the impact of clinicians engaging in early and regular GOC discussions on “in-the-moment decision-making” and goal concordant care (191, 275). The palliative care field is making progress in developing measures of goal concordance (276) and applying them in research studies. Approaches toward managing common symptoms in respiratory illnesses, such as acute breathlessness, cough, and fatigue, require further investigation to improve the efficacy of patient and caregiver self-care management as well as their QOL. For example, the effectiveness of specific opioid formulations and routes as well as target

illnesses has not been established. Furthermore, the effects in daily life of supplemental oxygen in patients without hypoxemia and the use of heliox on dyspnea and functional ability are unknown (277). In addition, studies on the effects of nonpharmacological approaches to symptom management, such as graded exercise therapy for fatigue, are important next steps to tailor care. Lastly, caregiver research is a priority as the demand for informal caregiver involvement in patient care increases while the caregiver population ages. Developing and evaluating dyad-targeted palliative care interventions for patients and caregivers living with serious respiratory illnesses is important as they may improve QOL, and this research can inform state and federal policy initiatives on caregiver support.

In summary, to comprehensively address the research priorities identified by the members of this committee (Table 9), it is imperative to engage a broad group of partners that includes patients, families, caregivers, policymakers, and funders (e.g., National Institutes of Health, Patient-Centered Outcomes Research Institute, and foundations) to help

prioritize topics and ensure adequate funding (264, 265).

Conclusions

Patients with serious respiratory illness and their caregivers suffer from significant physical, emotional, spiritual, and financial burdens and are in need of early palliative care to help guide treatment planning. Ideally, primary palliative care should be initiated by pulmonary–critical care clinicians early in the care continuum seamlessly alongside disease-directed treatments. Secondary palliative care has an important complementary role in supporting primary palliative care by providing interprofessional expertise as needed. Given the robust evidence-based support for palliative care in improving QOL among patients with serious illness, the provision of this care is a fundamental right for any patient and/or caregiver who may benefit. This multisociety policy statement presents essential palliative care recommendations, values, and guiding principles among patients with serious respiratory illness and is designed to provide guidance for clinicians and to inform policy initiatives. ■

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