

Developing a Research Agenda for Integrating Palliative Care into Critical Care and Pulmonary Practice To Improve Patient and Family Outcomes

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Abstract

Background: Palliative care is a medical specialty and philosophy of care that focuses on reducing suffering among patients with serious illness and their family members, regardless of disease diagnosis or prognosis. As critical illness or moderate to severe pulmonary disease confers significant disease-related symptom burdens, palliative care and palliative care specialists can aid in reducing symptom burden and improving quality of life among these patients and their family members.

Objective: The objective of this article is to review the existing gaps in evidence for palliative care in pulmonary disease and critical illness and to use an interdisciplinary working group convened by the National Institutes of Health and the National Palliative Care Research Center to develop a research agenda to address these gaps.

Methods: We completed a narrative review of the literature concerning the integration of palliative care into pulmonary and/or critical care. The review was based on recent systematic reviews on these topics as well as a summary of relevant articles identified through hand search. We used this review to identify gaps in current knowledge and develop a research agenda for the future.

Results: We identified key areas of need and knowledge gaps that should be addressed to improve palliative care for patients with pulmonary and critical illness. These areas include developing and validating patient- and family-centered outcomes, identifying the key components of palliative care that are effective and cost-effective, developing and evaluating different models of palliative care delivery, and determining the effectiveness and cost-effectiveness of palliative care interventions.

Conclusions: The goal of this research agenda is to encourage researchers, clinicians, healthcare systems, and research funders to identify research that can address these gaps and improve the lives of patients with pulmonary and critical illness and their family members.

Keywords: critical care; palliative care research; pulmonary disease

Introduction

PALLIATIVE CARE FOCUSES on improving quality of life and reducing suffering for patients with serious illness and their families.¹ Palliative care can be provided by non-specialist front-line providers (often termed primary pallia-

tive care) or by an interdisciplinary specialist team with advanced training and skills in symptom management and communication about prognosis, goals of care, and treatment options (often termed specialty palliative care).² Several authors outline this important conceptual approach to implementing palliative care²⁻⁴ (Table 1).

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Accepted January 3, 2017.

TABLE 1. CONCEPTUAL MODELS FOR PALLIATIVE CARE DELIVERY

Quill and Abernethy ²	Primary palliative care	Basic management of pain, symptoms, depression, and anxiety Basic discussions about prognosis, treatment goals, suffering, and code status
	Specialty palliative care	Management of refractory or more complex symptoms Assistance with conflict resolution regarding goals or methods of treatment Assistance in addressing cases of potentially inappropriate care
Institute of Medicine Report ³	Basic palliative care	Palliative care that is delivered by healthcare professionals who are <i>not</i> palliative care specialists, such as primary care clinicians, physicians who are disease-oriented specialists (such as oncologists and cardiologists), nurses, social workers, pharmacists, chaplains, and others who care for this population, but are not specialists in palliative care.
	Specialist palliative care	Palliative care that is delivered by healthcare professionals who <i>are</i> palliative care specialists, such as physicians who are board certified in this specialty, palliative care nurses, and palliative care-trained social workers, pharmacists, and chaplains.
IPAL-ICU ⁴	Integrative palliative care	Palliative care provided by the ICU team.
	Consultative palliative care	Palliative care provided by a non-ICU, palliative care consultation service.

ICU, intensive care unit; IPAL-ICU, improving palliative care in the ICU.

While palliative care is often confused with end-of-life care,¹ it is important to educate clinicians as well as patients and families that palliative care is much broader than end-of-life care. Equating palliative care and end-of-life care falsely presumes that clinicians have prognostic certainty about a patient's impending death⁵; even with the most robust models, prognostic certainty is rare and discussion of prognosis is influenced by patient-clinician relationships.⁶ Moreover, this conflation undervalues the benefits of palliative care for seriously ill patients who are not imminently dying—benefits such as symptom management, psychosocial support, and advance care planning. Importantly, palliative care can be provided in concert with curative or restorative treatments and other care teams in a coordinated, or integrated, approach to optimize quality of life and patient and family psychosocial support *regardless of disease prognosis or treatment goals*.⁷ This coordinated approach is particularly beneficial for patients with critical and/or pulmonary illness and is recommended by multiple pulmonary and critical care professional societies and expert consensus panels^{8–11} and by critically ill patients and their family members.¹² Further information on the specific content of palliative care, differentiation between palliative and end-of-care, and evidence supporting the benefits of palliative care can be found in a recent review on the topic.¹

This narrative review summarizes the current state of the science for palliative care for patients with critical illness or pulmonary disease, identifies gaps in current knowledge, and uses an interdisciplinary group convened by the National Institutes of Health and the National Palliative Care Research Center to develop a research agenda to address these gaps. Interdisciplinary group members were chosen based on their past publications and content expertise concerning these topics. Knowledge and research gaps were identified through discussion between group members. Existing palliative care studies have been completed in both North America and Europe and thus, these recommendations likely pertain to a diverse geographic clinician audience.

State of the Science for Palliative and Critical Care

Critically ill patients often require the most sophisticated technological treatment that modern medicine has to offer and are at significant risk for mortality both during and after intensive care unit (ICU) care.^{13–17} These patients are also at risk for significant morbidity with physical and psychological suffering that can occur both during and after ICU care.^{18–31} Family members and caregivers of ICU patients are also at risk of morbidity, especially psychological morbidity.^{31–38} The ICU has long been recognized as a frequent place of patient death.^{13–15,39} These deaths often follow a decision to withhold or withdraw life-sustaining treatments when those treatments no longer meet the patient's goals of care as deemed by the patient, family member, and/or clinicians.^{39–41} Observational studies validate the importance of improving palliative care in the ICU and identify specific targets for palliative care interventions.

Globally, our populations are aging and there is a dramatic increase in the population of patients living with chronic life-limiting illness and multimorbidity.⁴² There are important knowledge gaps regarding palliative care in the ICU, especially for older adults. None of the ICU-based palliative care studies specifically targeted older adults, and associated comprehensive reviews do not address needs or interventions specific for older patients. However, in assessing the component, 37 published studies in one systematic review on ICU-based palliative care⁴³; 22 studies reported patient age and these study populations together had a mean weighted age of 61.6 years. Seven of these studies were in ICU populations with a mean patient age greater than 65 years^{44–50} (Table 2).

Summary of research evaluating interventions to improve palliative care

Data for this article were drawn from systematic^{44,51,52} and comprehensive narrative^{53,54} reviews on palliative care in the ICU. Interventions can be grouped into broad domains based

TABLE 2. SAMPLE OF INTENSIVE CARE UNIT-BASED PALLIATIVE CARE STUDIES FOR OLDER ADULT (AGE ≥65 YEARS) POPULATIONS

Study	Study objective	Study setting	Sample	Mean age (years)	Study design	Finding
Carlson et al. ⁴⁸	Transition of patient care from ICU team to comprehensive support care team	MICU	n = 93; Patient is deemed hopelessly ill by ICU team, with common diagnoses, including severe neurologic injury, post-CPR anoxic encephalopathy, or end-stage malignancy	67	Before and after single-center trial	Reduced hospital LOS (33 to 10 days; $p < 0.05$); Reduced hospital charges (\$36.2K to \$13.2K; $p < 0.05$); No change in ICU LOS or mortality.
Schneiderman et al. ⁵⁰	Triggered ethics consult	Unspecified	n = 551; Patients for whom value-laden treatment conflicts were imminent or manifest	67.5	Prospective, multicenter, patient-randomized controlled trial	Among decedents: reduced ICU LOS ($p = 0.03$), hospital LOS ($p = 0.01$), ventilation days ($p = 0.03$); no change in mortality, artificial nutrition/hydration days.
Campbell and Guzman ⁴⁴	Triggered palliative care consultation	MICU	n = 81; Patients with terminal dementia admitted to an ICU	81	Before and after single-center trial	Reduced ICU and hospital LOS (6.8 to 3.5 days, 12.1 to 7.4 days; $p < 0.004$, $p < 0.007$, respectively); Fewer interventions for DNR patients (TISS 16.89 to 8.65; $p < 0.01$)
Lautrette et al. ⁴⁶	Family brochure, clinician education, and intensive communication with family using VALUE format to meetings	MICU, SICU, and mixed medical-surgical ICUs	n = 126; Patients who were deemed likely to die within a few days by the ICU attending physician	71	Prospective, multicenter, patient-randomized controlled trial	Reduced family member IES ($p = 0.02$), PTSD prevalence (69% to 45%; $p = 0.01$), and HADS score ($p = 0.004$); no change in ICU LOS or mortality.
Norton et al. ⁴⁷	Palliative care consultation	MICU	n = 191; Patients deemed as having a serious illness and at high risk of dying.	79	Before and after single-center trial	Reduced ICU LOS (16.3 to 9.0 days; $p = 0.001$); no change in hospital LOS or mortality.
Curtis et al. 2011 ¹⁰⁶	Clinician education, local champions, feedback to clinicians, and order sets	MICU, SICU, and mixed medical-surgical ICUs	n = 2310; Targeted hospitals and ICU, not individual patients or patient populations	71	Prospective, multicenter, cluster-randomized controlled trial	Increased number of family conferences within 72 hours of admission and prognosis discussed during meeting ($p < 0.001$, $p = 0.04$, respectively); no change in family or nurse QODD, ICU LOS, or FS-ICU score.
Penrod et al. ⁴⁹	Family toolkit with family meeting pocket cards for ICU clinicians, family brochures, and ELNEC training and communication skills workshops for ICU nurses	Unspecified	n = 415; Targeted entire ICU, not individual patients or patient populations	70	Before and after multicenter trial	Increase in identification of surrogates ($p < 0.05$), family meetings convened within five days of admission ($p < 0.05$), meeting being interdisciplinary ($p < 0.05$); decrease in determination of advance directives ($p < 0.01$); no change in investigation of resuscitation status.

CPR, cardio pulmonary resuscitation; DNR, do-not-resuscitate order; ELNEC, End-of-Life Nursing Education Curriculum; FS-ICU, family satisfaction in the ICU; HADS, Hospital Anxiety and Depression Score; IES, Impact of Event Scale; LOS, length of stay; MICU, medical intensive care unit; PTSD, post-traumatic stress disorder; QODD, Quality of death and dying Score; SICU, surgical intensive care unit; TISS, Therapeutic Intervention Scoring System.

TABLE 3. EXAMPLES OF INTENSIVE CARE UNIT-BASED PALLIATIVE CARE INTERVENTIONS AND REPRESENTATIVE STUDIES

Primary target	Examples	Summary of findings	Sample of references
Patient	NONE		
Family	Intervention booklet for family; intensive nurse-, social worker-, or physician-led communication; standardized or structured family meetings; family support coordinator or navigator; family presence during ICU rounds	Mixed—no effect or change in family satisfaction or depression scores, reduced ICU LOS, reduced nonconsensus between ICU clinicians and families; increased DNR and comfort care orders; increased order choosing aggressive interventions; improved frequency of communication with ICU providers; decreased ICU costs	Curtis et al. ⁵⁷ ; Daly et al. ⁸⁹ ; Medland and Ferrans ⁹⁰ ; Lilly et al. ^{91,92} ; Azoulay et al. ⁹³ ; Burns et al. ⁹⁴ ; Jacobowski et al. ⁹⁵ ; Ahrens et al. ⁹⁶ ; Shelton et al. ⁹⁷
Clinician team	Education about ethics; education about communication skills; Palliative care team rounds with ICU team	Increased proportion of ICU patients receiving palliative care consultation; reduced ICU LOS	Holloran et al. ⁹⁸ ; Villarreal et al. ⁹⁹
System	Palliative care or comfort care order set	No change; increased pastoral care involvement; reduced hospital LOS	Treece et al. ¹⁰⁰ ; Hall et al. ¹⁰¹
Multilevel	Palliative care consultation; ethics team consultation; transition of patient out from ICU team to comprehensive support care team; ICU clinician education about communication and more frequent and intensive communication with family; clinician education about palliative care communication with designation of local champions and standardized comfort care order sets; communication facilitator	No change; reduced ICU and hospital LOS; reduced treatment intensity; reduced depression, anxiety, and PTSD prevalence among family members; improved nurse QODD scores; increased frequency of family conferences; increased frequency of prognosis being discussed in family conferences; increased DNR status designation	Lautrette et al. ⁴⁶ ; Norton et al. ⁴⁷ ; Carlson et al. ⁴⁸ ; Schneiderman et al. ^{50,56} ; Field et al. ¹⁰² ; Dowdy et al. ¹⁰³ ; Campbell and Guzman ^{44,104} ; Curtis et al. ^{45,57,105} ; Lamba et al. ¹⁰⁶

on the intervention target (Table 3), although some interventions are “bundled” with multiple targets. These reviews all note that ICU-based palliative care interventions are highly heterogeneous such that comparison or broad effectiveness statements are challenging.

Recent influential studies related to ICU-based palliative care include the following:

- A large ($n=384$), single-center, patient-randomized controlled trial⁵⁵ of proactive ethics consultations for a diverse group of critically ill patients. This was a negative trial with no impact on length of ICU or hospital stay, cost, or nonbeneficial treatments and it stands in contrast to previous positive trials that targeted patients for whom value-related treatment conflicts arose.^{50,56}
- A large ($n=268$), two-center, parallel-group, patient-randomized controlled trial⁵⁷ of a communication facilitator who had a goal of improving communication between clinicians and the families of critically ill patients. The involvement of communication facilitators was associated with decreased family depressive symptoms at six months, but not at three months and with no change in family anxiety or post-traumatic stress disorder (PTSD) symptoms; the intervention decreased costs among all patients and particularly among decedents and reduced ICU and hospital length of stay (LOS).

- A large ($n=365$ family surrogates), multicenter, patient-randomized controlled trial⁵⁸ of a palliative care specialist-trained communicator who met with the family members of chronically critically ill patients once or twice to specifically discuss prognosis and with a primary outcome of family member anxiety and depression levels; this was a negative trial with no difference in anxiety and depression at three months, but higher PTSD symptoms in the intervention group.

In conclusion, the integration of palliative care and critical care most likely reduces ICU admissions, ICU length of stay, and treatment intensity with mixed evidence regarding its effect on family emotional outcomes, including studies showing improvement and other studies showing no improvement with a few studies suggesting harm. There are no data suggesting that proactive ICU-based palliative care worsens either ICU mortality or family satisfaction.

Knowledge gaps

As exemplified by the above studies, knowledge gaps include the following:

- Which critically ill patients and families are most likely to benefit from proactive, ICU-based palliative care?

- Which care models of ICU-based palliative care (primary, specialist, and/or mixed) are most effective in what types of ICU structures and/or cultures?
- How to best identify patients and families at high risk of having unmet palliative care needs or worse palliative care outcomes?
- What components of palliative care are most important for improving patient and family outcomes and what are the most effective ways to implement these components?
- What outcomes are most valid and responsive in determining effectiveness of ICU-based palliative care interventions and what is the impact of ICU-based palliative care interventions on these outcomes?

Priorities for next steps (Table 4)

Future studies should focus on developing, identifying, refining, and/or validating outcomes responsive to ICU-based palliative care and using these outcomes to evaluate varying models of palliative care delivery for critically ill patients and their families. The studies should focus on intervention development and evaluation to determine the effectiveness and cost-effectiveness of: ICU-based palliative care for both patients who die and those who survive, as well as for their family

members; and preventing ICU admission for patients for whom ICU care is not consistent with their informed goals of care.

State of the Science for Palliative Care and Pulmonary Disease

Key pulmonary diseases, including chronic obstructive pulmonary disease (COPD), interstitial lung disease (ILD), cystic fibrosis, and pulmonary hypertension, are life-limiting noncurable illnesses. Consequently, treatments for these conditions should include palliation with improvement of symptoms and quality of life, as well as slowing or halting progression of disease. While, palliative care has been best studied and implemented among patients with cancer, it has also been shown to be beneficial for patients suffering from lung disease, particularly chronic obstructive lung disease (COPD).⁵⁹

The World Health Organization lists COPD as one of the most common conditions for which palliative care is an appropriate yet underutilized service.⁶⁰ COPD is the leading cause of respiratory-related deaths and is the fourth leading cause of mortality globally.⁶¹ The disease trajectory for COPD is variable and characterized by prognostic uncertainty. Patients with advanced COPD usually experience a gradual but progressive decline in quality of life and exercise

TABLE 4. RESEARCH PRIORITIES FOR PALLIATIVE CARE RESEARCH IN CRITICAL CARE

<i>Research priority</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Study design</i>
Development and validation of outcomes	Validate diverse outcomes of palliative care in critical care setting	Academic and community-based ICUs	Critically ill patients and their family members	Prospective cohort studies
Identify patients and family members at risk for poor palliative care outcomes	Identify patients and family members most likely to benefit from palliative care interventions	Academic and community-based ICUs	Critically ill patients and their family members	Prospective cohort studies; retrospective and secondary database studies
Determination of effective and cost-effective interventions	Evaluate interventions	Academic and community-based ICUs	Critically ill patients and their family members	Randomized trials, including patient-level randomization and cluster randomization; innovative experimental designs
Identification of effective components of multifaceted interventions	Describe the most effective components of multifaceted interventions	Academic and community-based ICUs	Critically ill patients and their family members	Qualitative and mixed methods studies running parallel to intervention studies
Evaluate interventions to prevent ICU admission for patients with chronic life-limiting illness for whom ICU care is not consistent with their informed goals of care	Evaluate efficacy and effectiveness of interventions for improving patient- and family-centered outcomes	Academic and community-based hospitals; community settings	Patients with chronic life-limiting illness	Randomized trials, including patient-level randomization and cluster randomization; innovative experimental designs
Identification and intervention to decrease health disparities related to palliative care in the ICU	Describe existing disparities; evaluate efficacy and effectiveness of interventions to reduce health disparities	Academic and community-based hospitals; community settings; diverse populations	Critically ill patients from diverse racial/ethnic/geographic populations	Qualitative and mixed methods studies; prospective, observational cohort studies; pilot studies for novel interventions

tolerance, as well as development of oxygen dependence, and a course that is typically punctuated by acute exacerbations.⁶² Exacerbations of COPD can be life-threatening and are associated with an increased risk of dying. Approximately 10% of patients hospitalized with an acute exacerbation of COPD die during the hospital admission.⁶³ This proportion increases to about one-fourth for patients who need invasive mechanical ventilation.⁶⁴ These data support integrating palliative care into the routine care of patients diagnosed with moderate to severe COPD to improve quality of life through relief of emotional and physical symptoms, establishing goals of care, and coordination of care. Important knowledge gaps exist supporting the benefits of specific palliative care interventions on patient-centered outcomes for patients with COPD.

Although palliative care for patients with COPD is less well developed than for patients with cancer,^{65,66} palliative care for other chronic pulmonary diseases is even more nascent. Patients with chronic ILD are less likely to receive palliative care than patients with cancer or patients with COPD⁶⁷ and tend to receive palliative care only very late in their illness trajectory.⁶⁸ Patients with ILD and pulmonary fibrosis report a desire to engage in discussions about end-of-life care, yet this need is generally unmet.⁶⁹ Similarly, patients with advanced pulmonary hypertension are also unlikely to receive palliative care services despite a high burden of symptoms and reduced quality of life.⁷⁰

Many patients with COPD and ILD are cared for in, and die in, secondary or tertiary referral centers.^{71–73} At the end stage of their disease, which can be difficult to define, increased patient and family support from the specialist palliative care team may be required with ongoing input from respiratory physicians. The patients' concerns that their disease might progress and their fear that they would die of breathlessness or suffocation need to be addressed. Patients are often reluctant to discuss these important fears with healthcare professionals.⁷⁴ Even once in the ICU, patients with COPD or ILD receive fewer indicators of palliative care than patients with cancer.^{63,67} Given the prevalence of patient fear, anxiety, and depression related to their illness and frailty, equipping providers with tools to help address patients' emotional distress is important.

Patients with chronic lung disease have a high burden of symptoms, as high or higher than patients with cancer and other chronic diseases.⁷⁵ Cough is a frequent and disturbing symptom in COPD, cystic fibrosis, and ILD, and protocols to relieve cough are needed.⁸ A hallmark of palliative care for chronic lung disease is related to the management of dyspnea.^{8,76} A combination of nonpharmacological and pharmacological interventions may be necessary to achieve the greatest benefit.^{77,78} Pulmonary rehabilitation, particularly at home, has been successful and has focused on use of oxygen therapy, medical air, opioids, breathing techniques, and learning to make simple movements.⁷⁹ Finally, emotional intelligence and other innovative self-management methods need to be further explored, as studies suggest benefits for patients with COPD. In addition, health coaching and other navigator interventions oriented to palliative care may be a feasible intervention as recently shown effective in a patient hospitalized with a COPD exacerbation (many of them eligible for palliative care).^{80–82} These studies provide preliminary evidence that is promising, but further research is needed.

Summary of research evaluating interventions to improve palliative care for patients diagnosed with COPD and other chronic pulmonary diseases

Few studies have specifically examined the benefits of palliative care in patients with COPD, although several include patients with multimorbidities, including COPD. The interventions vary from targeted symptom management,^{83–86} outpatient palliative care services,⁸⁴ supporting clinicians' communication about goals of care and end-of-life care,⁸⁷ and advance care planning⁸⁸ (Table 5). Despite heterogeneity of the current interventions, studies support the integration of palliative and pulmonary care for patients diagnosed with COPD and their caregivers for improving symptom burden and quality of life, as well as reducing healthcare utilization, improving clinician communication skills, and increasing concordance of care received with patients' informed goals of care. There are even fewer studies examining the benefits of palliative care for patients with other chronic pulmonary diseases.

A couple of interventions are worth highlighting. A recent study evaluating a palliative breathlessness intervention found significant improvement in the individual's ability to cope with breathlessness.⁸⁴ Another study examined a sub-specialized multidisciplinary team (MDT), suggesting that such teams can build trust and knowledge about palliative care in patients and providers.⁷² The MDT includes patients as well as clinicians; patients with a range of disease severity, including some with very severe disease, serve as expert advisors for other patients.⁷¹ Finally, the provision of palliative care as the default option (patients need to opt out if they do not want it) has been recently considered and is currently being tested.⁸¹

Knowledge gaps

As exemplified by the above studies, knowledge gaps for patients with COPD and other chronic pulmonary disease include the following:

- What are the most effective and cost-effective pharmacological and nonpharmacological interventions to reduce symptoms and increase quality of life?
- What is the value and mechanism for early integration of palliative care?
- Which are the most valid and responsive patient-centered outcome measures?
- What are the most effective ways to implement advance care planning and goals of care discussions?
- What are the most effective models of palliative care delivery?
- What are the specific components of palliative care that are most useful and the best way to identify the patients and family members most likely to benefit?
- What interventions are most effective and cost-effective for managing dyspnea crisis and other symptoms?
- What are the barriers to better collaboration between nonmalignant lung disease and palliative care services?

Priorities for next steps (Table 6)

Future studies should focus on developing, identifying, and/or validating outcomes responsive to palliative care and

TABLE 5. SUMMARY OF PALLIATIVE CARE INTERVENTIONS FOR PATIENTS WITH PULMONARY DISEASE

Study	Study objective	Study setting	Sample	Mean age (years)	Study design	Findings
Individual studies Higginson et al. ⁸³	Assessing the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness.	Patients were enrolled from three large teaching hospitals and through general practitioners in South London, UK.	105 patients enrolled, 83 completed assessment at six weeks	67	Randomized, controlled, parallel group, pragmatic, single-blind fast-track trial	Mastery of breathlessness improved in the intervention compared with the control. Survival rate from randomization to six months was better in the breathlessness support service group than in the control group.
Detering et al. ⁸⁸	Investigating the impact of advance care planning on end-of-life care in elderly patients.	Patients admitted under internal medicine, cardiology, or respiratory medicine in a large university hospital in Melbourne, Australia.	309 legally competent medical inpatients who were >80 years old	Median intervention group 85; control group 84	Prospective, randomized controlled trial	Intervention reduced proportion of patients admitted to the ICU and resulted in high levels of family satisfaction and lower levels of family symptoms of anxiety and depression.
Rocker and Verma ¹⁰⁷	Commentary describing a pan-Canadian quality improvement program (INSPIRED) supporting multidisciplinary healthcare teams to bridge the chasm between evidence and practice, focused on enhancing patient confidence to manage their illness more effectively in their homes and communities.	First implemented at Queen Elizabeth II Health Sciences Centre (QEII HSC) in Halifax, Nova Scotia, Canada.	257 patients enrolled; 131 patients completed the program	Not included	Observational cohort study using patients as their own controls	Patients who completed the full program had fewer ED visits, fewer hospital admissions, fewer days in hospital compared with their utilization before enrollment and these reductions persisted for an additional subset of patients in a 12-month pre-post comparison.
Au et al. ⁸⁷	Assessing whether an intervention using patient-specific feedback about preferences for discussing end-of-life care would improve the occurrence and quality of communication between patients with COPD and their clinicians.	Outpatient clinics at the Veterans Affairs Puget Sound Healthcare System	376 randomized; 306 completed the study	69.4	Cluster-randomized trial that was randomized by clinicians	Patients in the intervention arm reported a nearly threefold higher rate of discussions about end-of-life care and also higher quality end-of-life communication.

(continued)

TABLE 5. (CONTINUED)

Study	Study objective	Study setting	Sample	Mean age (years)	Study design	Findings
Currow ¹⁰⁸ et al.	Assessing if oxygen administration results in symptomatic benefit of breathlessness.	Outpatients; Perth, Western Australia	413 outpatients	69.7	Consecutive cohort of patients seen over a four-year period (<i>post hoc</i> analysis of prospectively collected data)	No clinically significant improvement in breathlessness.
Currow ¹⁰⁹ et al.	Describing the pattern of response of breathlessness intensity to morphine dose escalation to inform dose titration in people who have responded in routine clinical care.	Outpatients with multiple morbidities; Perth, Western Australia	17 patients with multiple conditions who required a morphine dose greater than 10 mg daily	Median 82	Secondary data analysis	Improvement in breathlessness was greatest in the first 24 hours of response after dose escalation with continued improvement for six more days, suggesting that further dose increases should not occur for at least one week.
Abernethy ¹¹⁰ et al.	Assessing the effectiveness of oxygen compared with room air delivered by nasal cannula for relief of breathlessness.	Outpatients with multiple morbidities in Australia, USA, and UK	239 patients with multiple conditions	73	Randomized, controlled double-blind trial	Oxygen delivered by nasal cannula provides no additional symptomatic benefit for relief of refractory dyspnea compared with room air. Room air delivered by nasal cannula can be considered an intervention.
Currow ⁸⁶ et al.	Determining the minimum effective once-daily dose of sustained-release morphine and whether net clinical benefits are sustained safely.	Palliative Care service outpatients and inpatients with multiple morbidities	83 patients with dyspnea caused by multiple conditions	74.6	Pharmacovigilance study (Phase II dose increment study and Phase IV effectiveness/safety study at 10% dyspnea improvement dose)	Ten milligrams of sustained-release oral morphine once daily is safe and effective for most people who respond.

(continued)

TABLE 5. (CONTINUED)

<i>Study</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Mean age (years)</i>	<i>Study design</i>	<i>Findings</i>
Systematic reviews Rabow et al. ¹¹¹	To review the evidence surrounding outpatient palliative care	Four well-designed randomized trials of palliative care, palliative care consultation in a primary care clinic, early palliative care comanagement or telephone, advance practice nurse-led psychoeducational intervention	Four well-designed randomized interventions in patients with COPD, advanced cancer, and other chronic conditions	N/A	Systematic review	Outpatient palliative care services can (1) improve patient satisfaction, (2) improve symptom control and quality of life, (3) reduce healthcare utilization, and (4) lengthen survival in a population of lung cancer patients.
Gomes et al. ¹¹²	Quantifying the effect of home palliative care services for adult patients with advanced illness and their family caregivers; examining the clinical effectiveness of home palliative care services on other outcomes	12 electronic databases up to November 2012; 23 studies (16 RCTs, 6 of high quality)	37,561 patients and 4042 family caregivers, patients largely not only with advanced cancer but also CHF, COPD, HIV/AIDS, and MS, among others	N/A	Systematic review	The results show home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without negatively impacting caregiver grief
Barnes et al. ¹¹³	Determining the effectiveness of opioid drugs in relieving the symptom of breathlessness in people with advanced disease receiving palliative care	26 studies; double-blind RCTs only reviewed	Total of 526 participants	N/A	Systematic review	The mean change from baseline dyspnea score was better in the opioid group compared with the placebo group for breathlessness; the four-minute walk evidence was conflicting with no significant changes in quality of life and with patients more likely to experience adverse effects in opioid group

COPD, chronic obstructive pulmonary disease; CHF, congestive heart failure; ED, emergency department; MS, multiple sclerosis; N/A, not applicable; RCTs, randomized controlled trials.

TABLE 6. PRIORITIES FOR NEXT STEPS FOR PALLIATIVE CARE RESEARCH IN PULMONARY DISEASES

<i>Research priority</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Study design</i>
Design and conduct large multicenter trials of pharmacological and nonpharmacological interventions to improve symptom management and palliative care for patients with COPD and other chronic pulmonary diseases	Evaluate interventions to decrease symptom burden and improve quality of life	Community based or hospital based	Moderate to severe COPD or other chronic pulmonary diseases	Quasi-experimental study designs; Randomized controlled trials
Determine effectiveness and comparative effectiveness of early vs. late integration of palliative care for patients with COPD	Evaluate interventions to decrease symptom burden, improve quality-of-life, and increase frequency of goals of care discussions and advance care planning	Community based or hospital based	Patients with moderate COPD or severe COPD; patients with other moderate or severe pulmonary diseases	Quasi-experimental designs; prospective and retrospective cohort studies; randomized controlled trials
Develop and validate outcome measures for pulmonary disease-specific palliative care delivery and advance care planning	Validate diverse outcomes of palliative care in chronic lung diseases, including goal-concordant care (treatment desired = treatment received)	Community based or hospital based	Any stage chronic pulmonary disease	Randomized controlled trials; Quasi-experimental study designs; Prospective and retrospective cohort studies
Design and evaluate the effect of dyspnea crisis interventions on patient and caregiver self-efficacy to manage acute dyspnea episodes	Improve patient and caregiver's knowledge and confidence of managing acute dyspnea crisis. Impact of the intervention on healthcare utilization (ER visits)	Community-based settings	Severe chronic pulmonary disease	Randomized controlled trials; Quasi-experimental study designs
Develop and test optimal models of palliative care service delivery to patients with COPD or other chronic pulmonary diseases	Home visits vs. telephone-based vs. other communication technology devices; cost-effectiveness or cost-neutral studies of various models; nurse-led interventions	Community based or hospital based	Patients with moderate to severe chronic pulmonary diseases	Randomized controlled trials; Quasi-experimental study designs; prospective and retrospective cohort studies
Standardized methodological approaches to investigating PC for patients with COPD or other chronic pulmonary diseases. (definitions, outcome measures, etc.)	Develop definitions and identify key outcome measurements across studies for robust systematic reviews and meta-analyses.	Community based or hospital based	Moderate to severe chronic pulmonary diseases	Prospective and retrospective cohort studies
Identification and interventions to decrease health disparities related to palliative care in patients with chronic lung diseases	Describe existing disparities; evaluate efficacy and effectiveness of interventions to reduce health disparities	Community or hospital based	Patients with chronic lung disease from diverse populations	Qualitative and mixed methods studies; prospective, observational cohort studies; pilot studies for novel interventions

ER, emergency room; PC, palliative care.

using these outcomes to evaluate varying models of palliative care delivery for patients with pulmonary disease and their family members. Future studies should also focus on identifying the components of palliative care that most benefit patients with chronic pulmonary disease as well as exploring the effectiveness and optimal timing for deployment of palliative care and advance care planning interventions in this population. Further research is also needed that specifically targets development and evaluation of dyspnea crisis interventions on outcomes important to patients with chronic pulmonary disease and their caregivers.⁷⁶

Discussion

Several themes cross cut across these diseases and populations: issues related to patients and caregivers, provider-based interventions, communication, models of care delivery and timing, disparities, and outcome measurement.

Patients with chronic lung disease and/or critical illnesses have high symptom burdens and mortality. Caregivers are important in both groups; family members are often called upon to be surrogate decision makers and are themselves at risk for poor outcomes. Thus, there is a need to better identify patients and caregivers who would benefit most from palliative care and to match the most useful components of palliative care to specific populations with specific needs. Healthcare providers are also a potential target study population, particularly in exploring and evaluating feasible and scalable models of palliative care delivery (including primary and specialty palliative care) for these specific populations.

Communication is another crosscutting theme. These populations often require intense communication to facilitate complex decision making, identify goals of care in the context of changes in prognosis or uncertain prognosis, and implement effective advance care planning. Future research opportunities include defining current communication practices; developing and implementing patient and family-centered outcome metrics for communication; and exploring and evaluating best models of communication delivery, which incorporate management of uncertainty, adapt to differences in patient, family, and clinician preferences, and respond to the complex system-level factors that influence communication.

Regarding models of care delivery and the timing of palliative care, future research should develop, implement, and evaluate varying models of care delivery, including consultative and comanagement services, palliative care consultation clinics, community-based palliative care models, and/or hospital-based palliative care models. Moreover, as patients traverse varying care settings and cope with multimorbidity, there are further opportunities to study comprehensive, palliative care-informed approaches for managing care transitions and multimorbidity.

Healthcare disparities in palliative care must also be carefully considered and investigated. Palliative care studies should be completed in diverse populations with attention toward illuminating and mitigating disparities that can exist at patient, caregiver, provider, and/or system levels. Ultimately, interventions should not only improve delivery of effective and patient and family-centered palliative care for populations with critical and/or pulmonary illness but also do

so in an equitable and culturally sensitive manner that does not facilitate, and possibly even ameliorates, preexisting disparities in care.

Finally, more outcomes research is needed, particularly in developing, validating, and implementing patient- and family-centered outcome measures that are meaningful to patients, family members, care providers, hospitals, and healthcare delivery systems. Optimal outcomes are sensitive to existing variations in care delivery across diverse settings as well as responsive to changes instigated through palliative care-related quality improvement and/or research-related interventions. Such outcomes should be identified and validated across care settings—critical care unit, inpatient hospital care, outpatient clinic care, and home-based care—for both patients and, when appropriate, caregivers. Mixed method as well as pure qualitative work will be essential in this work. Research must also further explore how to measure the essential outcome of goal-concordant care.

Conclusions

Patients with pulmonary and critical illness, and their families, often have significant palliative care needs, including: a high symptom burden; poor quality of life; inadequate communication about the goals of care; difficulty with, and inadequate support in, decision making about treatment options; and insufficient emotional, social, and spiritual support. We used a pulmonary and critical care provider expert panel as well as an interdisciplinary group convened by the National Institutes of Health and the National Palliative Care Research Center to develop a research agenda to address these palliative care needs. The goal of this research agenda is to encourage researchers, clinicians, healthcare systems, and research funders to develop, implement, and support research that can address these gaps and improve the lives of patients with pulmonary and critical illness and their family members.

Acknowledgments

The authors wish to thank R. Sean Morrison, Basil Eldadah, and all participants at the National Institutes of Health–National Palliative Care Research Center joint conference on palliative care research priorities in medical subspecialties convened on August 2 and 3, 2016, in Bethesda, MD.

Author Disclosure Statement

No competing financial interests exist.

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