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"Recent Advances in Pulmonary  
Rehabilitation"

## Literature Review

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# A Review of Non-Pharmacological Pulmonary Rehabilitation for Patients Receiving Palliative Care

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## ABSTRACT

**Introduction:** Dyspnea is common in patients experiencing chronic and malignant lung conditions. It is a very distressing symptom that often results in anxiety and depression. Pulmonary rehabilitation together with palliative care can provide physical, psychological, and quality of life (QoL) improvements in patients that receive it.

**Methods:** This literature review examined articles published in the last 5 years to give a current summary of the scientific literature regarding pulmonary rehabilitation for persons receiving palliative care treatment. Focus was placed on patients with chronic obstructive pulmonary disease, cancer, interstitial lung disease, and Huntington's disease. From an initial 218 articles, 56 met the inclusion criteria for this review.

**Results:** Prominent themes that emerged were the beneficial effects of pulmonary rehabilitation, even in late stages of lung disease, and the positive impact palliative care can have on the patient. Simultaneously, there were considerable barriers to access mentioned throughout the literature, which prevents patients from receiving either pulmonary rehabilitation and/or palliative care at the end-of-life. Educating health care providers on the benefits of pulmonary rehabilitation, and providing timely referrals to pulmonary rehabilitation and palliative care is important. Understanding factors which may prompt a patient to attend and complete, or discontinue, pulmonary rehabilitation treatment is important.

**Conclusion:** Although, pulmonary rehabilitation itself is beneficial, meeting the patient where they are at and pairing rehabilitation with patient empowerment and motivating therapies such as mindfulness-based therapy may improve the patient's QoL and care at the end-of-life. Most pulmonary rehabilitation programs are focused and tailored to patients with chronic obstructive pulmonary disease. Exploring how tailored pulmonary rehabilitation programs may be effective in other populations, such as patients with interstitial lung disease, Huntington's disease, and end-stage cancer, is warranted.

**KEY WORDS:** End-of-life; Intervention; Dyspnea.

**ABBREVIATIONS:** COPD: Chronic Obstructive Pulmonary Disease; CRDs: Chronic Respiratory Diseases; ATS: American Thoracic Society; ERS: European Respiratory Society; BIS: Breathlessness Intervention Service; BSS: Breathlessness Support Service; CAPs: Clinical Assessment Protocol.

## BACKGROUND

Dyspnea, often referred to as shortness of breath or difficulty in breathing, is a subjective experience.<sup>1</sup> Although, objective values such as respiratory rate, blood oxygen content, or lung function can be determined, they often only moderately correlate with the patient's subjective

tive assessment of their dyspnea.<sup>1</sup> Dyspnea and cough, common symptoms in patients receiving palliative care, are present in the majority of patients with non-malignant conditions (experienced by 60-100% of patients) as well as in patients with advanced cancer (experienced by 10-70% of patients).<sup>1</sup> Dyspnea is shown to be associated with a diminished will to live, and in patients with a prognosis of less than 6 months, it is associated with shorter survival.<sup>1</sup> Dyspnea not only affects the patient, but also the people around them. Informal caregivers of patients experiencing dyspnea are more likely to experience distress as compared to caregivers of clients not experiencing dyspnea.<sup>2</sup> Chronic respiratory diseases (CRDs) and some malignancies often cause dyspnea and are a natural part of the disease process. However, emotional feelings of fear or loneliness can exacerbate dyspnea.<sup>1</sup> Since dyspnea itself causes fear and panic in the patient, a vicious cycle of dyspnea-fear-dyspnea can worsen shortness of breath. Therefore, shortness of breath can be a complex symptom, resulting from an interplay between physiology and emotion, in which one treatment modality often will not offer adequate symptom relief. Pulmonary rehabilitation which encompasses tailored therapies that aim to help the physical as well as the psychological health of the patient is therefore an important consideration for patients receiving palliative care. For the purpose of this review the definition of pulmonary rehabilitation will be used from the American Thoracic Society (ATS) and the European Respiratory Society (ERS): “Pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies that include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with CRD and to promote the long-term adherence to health-enhancing behaviors.”<sup>3</sup> This review excludes pharmacological interventions and O<sub>2</sub> ventilation from its scope, as the review’s specific focus is of non-pharmacological pulmonary rehabilitation treatment.

The World Health Organization (WHO) defines palliative care as, “An approach that improves the quality of life (QoL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” In other words, both pulmonary rehabilitation and palliative care strive to use a multidisciplinary approach to tailor therapies to the patient in hopes of encouraging physical and psychological well-being. The end goal of pulmonary rehabilitation among a palliative population nearing end-of-life is not to cure advanced stage disease, but rather to enhance the QoL and death of the patient. Although, there are similarities between pulmonary rehabilitation and palliative care, there are also differences in their approaches. Pulmonary rehabilitation is usually hospital-based and focuses on exercise, promotion of health behaviours, and raising functional status.<sup>4</sup> Physiotherapists, respiratory therapists, and other pulmonary rehabilitation health providers can show patients physical exercises, positioning, and breathing exercises so that the patients

themselves can take an active role in symptom management. Often as the disease progresses, patients experience mixed emotions. Rehabilitation can help to realign patients to their new reality and set new goals. The rehabilitation model itself can switch from a restorative goal to one of palliative rehabilitation that focuses on relieving symptoms and enabling the patient to maintain a good QoL. Even if the patient themselves can no longer benefit functionally from rehabilitation, staff can teach family members or caregivers how to improve patient comfort.<sup>5</sup>

Palliative care on the other hand provides whole person centred-care to the patient as well as members of their circle of care including informal caregivers, family, and friends over a wide range of domains including; disease and physical symptom management, psychological, social, and spiritual well-being, assisting with practical aspects of daily living, end-of-life care and death management as well as loss and grief counselling.<sup>6</sup> This paper will focus on non-pharmacological pulmonary rehabilitation for patients receiving palliative care and will address specific respiratory conditions of: chronic obstructive pulmonary disease (COPD), cancer, interstitial lung disease, and Huntington’s disease.

## METHODS

### Identification of Relevant Studies

Four databases (PubMed, OVID Medline, EBSCO PsycINFO, and EBSCO CINAHL) were used in the search for relevant studies on the topic of pulmonary rehabilitation in the setting of palliative care. Keyword and subject heading search terms included combinations of “pulmonary or respiratory rehabilitation” and “palliative care or end-of-life care or terminal care or hospice care”. The search was limited to studies published in the past 5 years, since 2012. The 5 year cut-off was selected as an appropriate point to be inclusive while remaining up-to-date. Articles were exported from the databases and managed in the referencing software program Endnote.<sup>63</sup>

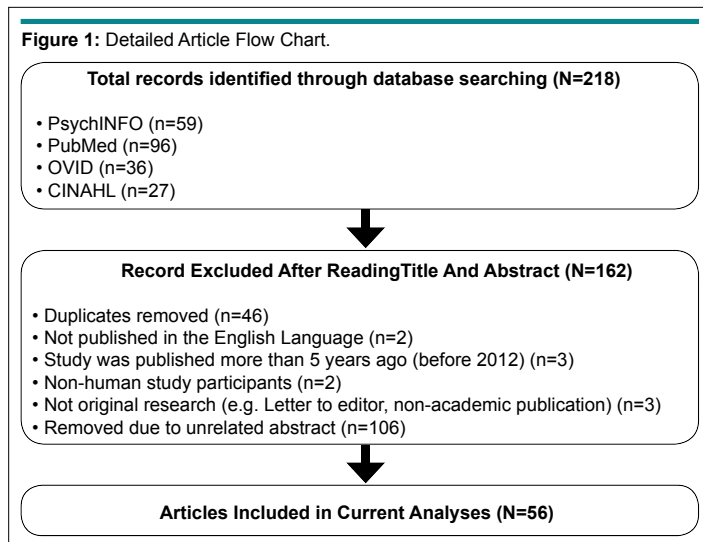
### Study Selection and Criteria

A detailed article flow chart with selection criteria can be found in Figure 1. Two-hundred and eighteen journal article titles were imported into Endnote, duplicates were removed and then titles and abstracts were examined to determine if the article met inclusion and exclusion criteria. Initially, 56 articles were removed as they were not published in the English language, used non-human subjects, published prior to 2012, or were not published as an article in a journal (ex., conference proceedings, editorials, and letters to the editor were excluded). Abstract and article screening was then performed. Articles were excluded if they included pharmacological treatments, oxygen ventilation, patients in the early stage of disease, the majority of patients had asthma, or if the articles did not specify which disease type their study population had. After screening from an initial 218 articles, 56 articles were included in the review.

**FINDINGS**

The majority of studies published focussed on patients with COPD (n=24)<sup>4,7-29</sup> in addition to multi-disease diagnoses studies (n=10)<sup>1,5,30-37</sup> where the majority of patients in the study sample

had a diagnosis of COPD. Patients with cancer diagnoses were the next studied population of focus (n=13),<sup>38-50</sup> followed by patients with interstitial lung disease (n=8),<sup>51-58</sup> and lastly one study focussed on patients with Huntington’s disease (Table 1).<sup>59</sup>



**Table 1:** Summary of Articles Included for This Literature Review (N= 56)

Articles Focussed on Patients with COPD Diagnosis							
Author	Institution, Country	Study Design	Sample Size	Disease of Focus	Study Objectives	Intervention	Main Findings
Benzo et al <sup>7</sup>	• Multiple institutions - USA (Part of NETT study)	Longitudinal	N=1,218	Patients enrolled in National Emphysema Treatment Trial (NETT) with severe COPD	“To determine if the change over time of key parameters in severe COPD patients can independently predict short-term mortality.” p.491	N/A	“...we found that in severe COPD patients, the trajectory to end-of-life is initially signaled by a decline in a physical function measure (six-minute walk/gait speed) or the development of a very severe sedentary life, followed by the onset of depressive symptoms, and a decline in oxygenation and eventually a decline in PCO2.” p.498
Benzo et al <sup>8</sup>	• Mayo Clinic, Rochester, MN, USA • Health Partners Foundation, St. Paul, MN, USA	Qualitative	N=712	Patients with COPD hospitalized due to exacerbation, who were not interested in enrolling in a pulmonary rehabilitation program	“The objective of this study is to investigate the knowledge gap on the underlying reasons for nonparticipation in pulmonary rehabilitation in the post hospitalization period” p.5	N/A	“The themes for not attending include lack of interest (39%), the perception of “being too ill or frail or disabled” (24%), the perception of being “too busy or having too much to do” (11%), distance or the need of travel (11%), commitment issues (7%), comorbidities (6%), and lack of social support (2%)” p.5
Boer et al <sup>9</sup>	• Radboud University, The Netherlands	Validation study	Exploratory factor analysis: n=145 patients. Confirmatory factor analysis: n=430	Exploratory factor analysis with patients with moderate to severe COPD; Confirmatory factor analysis with patients with mild to very severe COPD	“... we investigated (1) whether the clinically observed stages of denial, resistance, sorrow, and acceptance can be identified as independent stages and (2) whether the ADIQ is a valid and reliable instrument to measure these stages.” p.562	N/A	“...the ADIQ can assess several stages of non-acceptance in patients with COPD, thereby it may be a very useful instrument to formulate patient-tailored treatment goals in clinical practice and to help increase patients’ motivation for self-management.” p 569
Long et al <sup>10</sup>	• National Jewish Health, Denver, CO, USA • University of Colorado School of Medicine at the Anschutz Medical Campus, Denver, CO, USA	Prospective, longitudinal, single arm mixed-method pilot study	N=15 patients	Patients with GOLD stage III or IV COPD	“The goal of this study was to evaluate the feasibility and usefulness of an advance practice nurse delivered palliative care intervention in patients with symptomatic COPD.” p.514	“Pharmacologic and non-pharmacologic palliative management of dyspnea, anxiety, and depression.” p.169	“The intervention was feasible based on the successful recruitment and 87%retention rate of participants and completion of survey measures” p.519

Cooke et al <sup>11</sup>	<ul style="list-style-type: none"> <li>School of Nursing Midwifery and Social Work, University of Manchester, Manchester, UK</li> <li>National Health Service Sheffield, Sheffield, UK</li> </ul>	Qualitative	Health professionals n=8, patients n=30, carers n=2	Patients with COPD	"The aim of the study was to define and compare the prioritized perspectives of respiratory specialist professionals and patients with COPD for expected outcomes of respiratory services." p. 1525	N/A	"Professionals cannot always interpret the needs of patients when commissioning health care or delivering services." p. 1531
Foster et al <sup>12</sup>	<ul style="list-style-type: none"> <li>Keele University, Keele, Staffordshire, UK</li> </ul>	Participatory Action Research design	Baseline survey of health care professionals n=22, patients n=126	Health care professionals who care for patients with COPD were general practitioners and nurses; patients had COPD	"Working with primary care clinicians (GPs and practice nurses) from eight practices, this project developed strategies for influencing clinician and patient behaviours as a means of increasing referral rates for pulmonary rehabilitation." p. 226	In-house education sessions and memory aids (coffee mugs) to prompt discussion around pulmonary rehabilitation	"The types of strategy introduced in this study were each relatively easy to implement and the anticipated pay-off is an increase in the number of patients accessing pulmonary rehabilitation and receiving the health and quality of life benefits that it delivers." p 237
Goodridge et al <sup>13</sup>	<ul style="list-style-type: none"> <li>University of Saskatchewan, Saskatoon, SK, Canada</li> </ul>	Feasibility study	N=19; n=14 in therapeutic arm; n=5 treatment as usual	Patients with advanced COPD	"Feasibility study to determine the impact of singing on COPD symptoms"	8-week therapeutic singing program	While the program was well received by participants, they did not find improvements in health-related quality of life, exercise capacity, or perceptions of illness compared to control
Harrison et al <sup>15</sup>	<ul style="list-style-type: none"> <li>University of Leicester, Leicester, UK</li> <li>West Park Healthcare Center, Toronto, ON, Canada</li> <li>Coventry University, Coventry, UK</li> </ul>	Qualitative	N=6 patients	Patients recently hospitalized with an acute exacerbation of COPD, who refused a referral to pulmonary rehabilitation	"To explore how patients who refuse referral to Pulmonary Rehabilitation appraise acute exacerbations of COPD, in the context of having considered and declined pulmonary rehabilitation." p. 750	N/A	"Prominent in these participants' narratives are self-conscious cognitions which appear founded in shame and stigmatization. These cognitions seem to reflect challenges to self-worth and appear associated with reduced help-seeking and isolation" p. 750
Harrison et al <sup>14</sup>	<ul style="list-style-type: none"> <li>West Park Healthcare Centre, Toronto, ON, Canada</li> <li>Teesside University, Middlesbrough, UK</li> <li>University of Toronto, Toronto, ON, Canada</li> </ul>	Qualitative	N=39; n=20 health care providers; n=19 patients with COPD	Health care providers with at least 1 year clinical experience with COPD management; Patients with moderate to severe COPD	"To explore the views of healthcare professionals and patients towards mindfulness for individuals with COPD." p. 337	N/A	"Mindfulness appears to be an attractive therapy for individuals with COPD. An understanding of the perspectives of HCPs and patients should inform the delivery of such programs" p. 337
Janssen et al <sup>16</sup>	<ul style="list-style-type: none"> <li>Centre of Expertise for Chronic Organ Failure, The Netherlands</li> <li>Maastricht University Medical Centre, Maastricht, The Netherlands</li> <li>University of Kentucky Medical School, Kentucky Clinic, Limestone, Lexington, KY, USA</li> </ul>	Review	N/A	COPD	"In this article, an overview of the complex needs and barriers involved in the provision of palliative care is provided, and how advance care planning education as a component of palliative care can be introduced during pulmonary rehabilitation is described." p. 412	N/A	"Patients with advanced COPD have unmet palliative care needs, such as high daily symptom burden, daily care needs, needs of family caregivers, and needs for advance care planning." p 418
Lin et al <sup>17</sup>	<ul style="list-style-type: none"> <li>National Taipei University of Nursing and Health Sciences, Taipei, Taiwan</li> <li>National Taiwan University Hospital, Yun-Lin Branch, Yun-Lin, Taiwan</li> <li>Chung Shan Medical University Hospital, Taichung, Taiwan</li> <li>Taichung Veterans General Hospital, Taichung, Taiwan</li> <li>National Yang-Ming University, Taipei, Taiwan</li> </ul>	Randomized controlled trial	N=40; intervention n=20, control n=20	Patients with GOLD stage II, III, or IV COPD	"To assess the effects of respiratory training on lung function, activity tolerance and quality of life in patients with chronic obstructive pulmonary disease." p. 2870	Pulmonary rehabilitation based intervention program	"A respiratory training programme for patients with chronic obstructive pulmonary disease was found to relieve dyspnoea, maintain lung function, increase activity tolerance and improve quality of life." p. 2870

Malpass et al <sup>18</sup>	<ul style="list-style-type: none"> <li>University of Bristol, Bristol, UK</li> </ul>	Phenomenology	N=22 patients, n=12 sampled for in-depth interviews (n=6 COPD, n=6 asthma)	Patients with a diagnosis of COPD or asthma and comorbid symptoms such as anxiety, depression, or low mood	<p>"The aim of this phenomenological study was to carry out in-depth qualitative interviews with a purposive sample of patients with asthma and COPD taking part in an 8-week mindfulness-based cognitive therapy (MBCT) course to explore their experiences of MBCT." p. 1181</p>	Mindfulness-based cognitive therapy	<p>"The qualitative interviews found that MBCT could facilitate a greater acceptance of respiratory illness and a reduced sense of perceived disease-related stigma." p 1189</p>
Mark et al <sup>19</sup>	<ul style="list-style-type: none"> <li>University of Hawaii at Mānoa, Honolulu, USA</li> <li>Kāhī Mōhala Behavioral Health, Honolulu, USA</li> </ul>	Randomized controlled trial (RCT)	N=24 patients	Patients with a diagnosis of COPD and self-reported shortness of breath with activity	<p>"This feasibility study measured the effect of pursed-lip breathing training delivered over Skype on dyspnea, physical activity, health-related quality of life, and self-efficacy." p.424</p>	Pursed-lip breathing taught over Skype	<p>"The intervention was found to be feasible and demonstrated marginal improvements in quality of life measures. ... using communication software for the education and management of patients with chronic diseases and their caregivers may be both effective and efficient and especially useful for those who are geographically dispersed or homebound." p. 424</p>
Marquis et al <sup>20</sup>	<ul style="list-style-type: none"> <li>University of Sherbrooke, Sherbrooke, QB, Canada</li> <li>Université Laval, Quebec City, QB, Canada</li> </ul>	Experimental	N=26 patients	Patients with moderate to very severe COPD	<p>"This study aims to investigate the effect of telerehabilitation on exercise tolerance and quality of life and to document patient satisfaction and adherence." p. 1</p>	15 in-home teletreatment sessions over 8 weeks via videoconference	<p>"The telerehabilitation program was associated with beneficial effects on exercise tolerance and quality of life and was well received by users." p. 1</p>
Mathar et al <sup>21</sup>	<ul style="list-style-type: none"> <li>Metropolitan University College, Copenhagen, Denmark</li> </ul>	Metasynthesis	6 studies (n=4 from the UK, n=2 from Australia); N=65 patients	Patients with COPD who declined to participate in pulmonary rehabilitation	<p>"This paper aimed to suggest possible answers to the question: Why do patients with COPD decline pulmonary rehabilitation?" p.432</p>	N/A	<p>"The studies included show patients' rational accounts and reflections on declining pulmonary rehabilitation. The included studies tend to describe accounts for deselection of pulmonary rehabilitation in relation to the preferences and beliefs of the patients rather than including the social and economic variables framing the behaviour and choices of the patients" p. 432</p>
McDonald et al <sup>22</sup>	<ul style="list-style-type: none"> <li>Austin Hospital, Melbourne, Victoria, Australia</li> </ul>	Review	N/A	COPD	<p>Discuss clinical perspectives in advances in COPD</p>	N/A	<p>"Pharmacologic and non-pharmacologic therapy can improve symptoms, quality of life and exercise capacity and, through their effects on reducing exacerbations, have the potential to modify disease progression. Comorbidities are common and require targeted treatment." p. 860</p>



Peters et al <sup>23</sup>	<ul style="list-style-type: none"> <li>Radboud University medical Center, Nijmegen, The Netherlands</li> </ul>	Longitudinal	Usual care n=160 patients; n=459 patients in pulmonary rehabilitation	Patients with moderate to severe COPD	<p>"The purposes of the study are to identify clinical phenotypes that reflect the level of adaptation to the disease and to examine whether these clinical phenotypes respond differently to treatment as usual and pulmonary rehabilitation." p. 1.</p>	Patients were either receiving treatment as usual or pulmonary rehabilitation	<p>"Different phenotypes exist in COPD that are based on behavioural aspects (i.e., the level of adaptation to the disease). Non-adapted patient responds better to treatments with a strong emphasis on improving adaptation by learning the patient better self-management skills." p. 1</p>
Reticker et al <sup>4</sup>	<ul style="list-style-type: none"> <li>Hartford Hospital, Hartford, CT, USA</li> <li>The Alpert Medical School of Brown University, Providence, RI, USA</li> <li>St. Francis Hospital &amp; Medical Center, Hartford, CT, UK</li> </ul>	Case study	N=1	COPD	<p>Presents discussion highlighting the similarities of "two important components of the integrated care model in the patient with chronic respiratory disease are pulmonary rehabilitation and palliative care" p. 107</p>	N/A	<p>"...pulmonary rehabilitation and palliative care, provided as part of comprehensive, multidisciplinary interventions, should be considered earlier in the course of COPD than is typical current practice." p.114</p>
Rice et al <sup>24</sup>	<ul style="list-style-type: none"> <li>Minneapolis VA Health Care System, Minneapolis, MN, USA</li> <li>McGill University Health Centre, Montréal, QB, Canada</li> </ul>	Review	N/A	COPD	<p>Describes collaborative self-management and behavioural change for improving health outcomes in patients with COPD.</p>	N/A	<p>"...team-based COPD CSM have been shown to improve outcomes, such as health status and health care utilization, in rigorously de-signed RCTs. However, self-management may not suit all patients." p. 347</p>
Solomon et al <sup>25</sup>	<ul style="list-style-type: none"> <li>The Ottawa Hospital Rehabilitation Centre, Ottawa, ON, Canada</li> <li>University of Ottawa, Ottawa, ON, Canada</li> </ul>	Mixed methods	N=195 patients	Patients with stage III or IV COPD admitted to a pulmonary rehabilitation program	<p>"The goals of this study were to examine whether loss of dignity is also a concern for patients receiving interdisciplinary rehabilitation for Stage III or IV chronic obstructive pulmonary disease. We examined the prevalence and correlates of loss of dignity and determined whether it improves with treatment." p.529</p>	Pulmonary rehabilitation	<p>"The prevalence of a problematic loss of dignity among patients with severe chronic obstructive pulmonary disease is at least as high as among those receiving palliative cancer care." p. 529</p>
Sully et al <sup>26</sup>	<ul style="list-style-type: none"> <li>Mount Sinai Hospital, Côte Saint-Luc, QB, Canada</li> <li>University of Montreal, Montreal, QB, Canada</li> </ul>	Qualitative	n=14 clinicians; n=23 patients	Patients with moderate to severe COPD	<p>"The purpose of this study was to develop a conceptual model for the assessment of patients' rehabilitation needs by using a grounded theory approach." p.76</p>	N/A	<p>"... that quality of life as a "sum total" cannot be measured, but individual patient's needs can and should be measured as markers of quality of life." p. 86</p>
Tselebis et al <sup>27</sup>	<ul style="list-style-type: none"> <li>General Hospital of Chest Disease, Athens, Greece</li> <li>Elena Venizelou Hospital, Athens, Greece</li> <li>Metropolitan General Hospital, Athens, Greece</li> <li>University of Crete Medical School, Heraklion, Greece</li> </ul>	Review	N/A	COPD	<p>"The objectives of this paper are to provide an overview of the prevalence, impact, and pathophysiology associated with anxiety and depression in patients with COPD and to review studies on pharmacological and nonpharmacological interventions." p.298</p>	N/A	<p>"Although the literature on treating anxiety and depression in patients with COPD is limited, we believe that it points to the implementation of personalized strategies to address their psychopathological comorbidities." p. 297</p>

van Dam van Isselt et al <sup>28</sup>	<ul style="list-style-type: none"> <li>Leiden University Medical Center, Leiden, The Netherlands</li> <li>Zorggroep Solis, Deventer, The Netherlands</li> <li>Deventer Hospital, Deventer, The Netherlands</li> </ul>	Prospective cohort study	N=61 patients	Patients with GOLD stage III or IV COPD admitted to hospital for acute exacerbation	"The aim of this study is to investigate the feasibility of the geriatric rehabilitation-COPD program" p. 111	Geriatric rehabilitation program	"Development and implementation of a postacute GR program for these patients are feasible and likely to offer substantial improvements." p. 111
Zoeckler et al <sup>29</sup>	<ul style="list-style-type: none"> <li>Philipps- University, Marburg, Germany</li> <li>Pulmonary Rehabilitation Centre, Schoenau, Germany</li> </ul>	Prospective cohort study	N=96 patients	Patients with GOLD stage III or IV COPD	"The aim of the present study was to investigate whether illness perceptions before pulmonary rehabilitation influence exercise capacity and quality of life after rehabilitation." p. 146	Pulmonary rehabilitation	"COPD patients' perceptions about their illness before rehabilitation influence exercise capacity and quality of life (psychological well-being) after treatment." p. 146
<b>Articles Focussed on Patients with A Cancer Diagnoses</b>							
Arthur et al <sup>38</sup>	<ul style="list-style-type: none"> <li>The University of Texas M. D. Anderson Cancer Center, Houston, TX, USA</li> </ul>	Case-report	N=1	Patient with metastatic non- small cell lung cancer	"We report the case of a patient with advanced cancer who got married in our acute palliative care unit weeks before her death." p. 466	N/A	"The wedding gave her the opportunity to acquire further meaning in life, deepen her connection with her loved ones, and enhance her sense of dignity, self-worth, and pride. It also was associated with a significant improvement in her symptoms and had a positive effect on the health care team." p. 466
Cheville et al <sup>39</sup>	<ul style="list-style-type: none"> <li>Mayo Clinic, Minnesota, USA</li> <li>Rehabilitation Institute of Chicago, Illinois, USA</li> </ul>	Randomized controlled trial	N=66 outpatient oncology clinic patients	Patients with stage IV lung or colorectal cancer	"To conduct an adequately powered trial of a home-based exercise intervention that can be facily integrated into established delivery and reimbursement structures." p. 811	8 week trial comparing incremental walking/usual care and home- based strength training	"A home-based exercise program seems capable of improving the mobility, fatigue, and sleep quality of patients with Stage IV lung and colorectal cancer." p. 811
Eickmeyer et al <sup>40</sup>	<ul style="list-style-type: none"> <li>Department of Physical Medicine and Rehabilitation at the Medical College of Wisconsin and Clement J. Zablocki VA Medical Center, Milwaukee, WI, USA</li> <li>Northwestern University Feinberg School of Medicine, and the Rehabilitation Institute of Chicago, Chicago, IL, USA</li> <li>University of Texas Southwestern Medical Center, Dallas, TX, USA</li> </ul>	Review	N/A	Cancer	"This article will familiarize physiatrists with the current state of evidence regarding the role and efficacy of exercise in persons with cancer." p. 874	N/A	"With improved awareness of the role of exercise along the cancer disease continuum, rehabilitation providers can use an evidence base to partner with the oncology community to develop critically needed exercise prescriptions and programs." p. 880
Ellis et al <sup>41</sup>	<ul style="list-style-type: none"> <li>University of Liverpool, Liverpool, United Kingdom</li> <li>University of Southampton, Southampton, UK</li> <li>Karolinska Institutet, Stockholm, Sweden</li> <li>LaTrobe University, Melbourne, Victoria, Australia</li> <li>Lancashire Teaching Hospitals, Lancaster, UK</li> <li>University of Manchester, Manchester, UK</li> <li>The Christie NHS Foundation Trust Manchester, UK</li> </ul>	Qualitative	n=37 patients with lung cancer; n=23 caregivers	Majority of patients had stage 3 or 4 lung cancer	"The objective of this study was to identify the views of patients with lung cancer and their informal caregivers on the desirable components of a novel nonpharmacological intervention for symptom management" p.831	N/A	"The data from this study have provided insight into the key issues that are likely to influence the development, uptake, and delivery of a nonpharmacological intervention to help manage the respiratory symptom cluster of cough, breathlessness, and fatigue" p.832
Farquhar et al <sup>42</sup>	<ul style="list-style-type: none"> <li>University of Cambridge, Institute of Public Health, Cambridge, UK</li> <li>University of Manchester, Manchester, UK</li> <li>King's College, London, UK</li> </ul>	Single-centre Phase III fast-track single-blind mixed-method randomized controlled trial	N=67 patients	Majority of patients had lung cancer (49%) and breast cancer (19%)	"To establish whether the Breathlessness Intervention Service was more effective, and cost-effective, for patients with advanced cancer and their carers than standard care " p.1	Breathlessness Intervention Service vs. standard care	"Breathlessness intervention service appears to be more effective and cost-effective in advanced cancer than standard care." p.1

Hui et al <sup>43</sup>	<ul style="list-style-type: none"> <li>M. D. Anderson Cancer Center, Houston, TX, USA</li> <li>Barretos Cancer Hospital, Barretos, Brazil</li> </ul>	Prospective observational study	N=357 patients	Advanced cancer patients admitted to an acute palliative care unit	"To examine the frequency, intensity, and predictors for symptoms in the last seven days of life among patients who were able to communicate and died in an acute palliative care unit." p.488	N/A	"Despite intensive management in acute palliative care units, some cancer patients continue to experience high symptom burden as they approached death" p. 488
Jensen et al <sup>44</sup>	<ul style="list-style-type: none"> <li>Center Eppendorf, Hamburg, Germany</li> <li>University of Cologne, Cologne, Germany</li> </ul>	Retrospective feasibility analysis	N=528 patients	Advanced cancer patients admitted to a specialized palliative care inpatient ward. Lung cancer was the mostcommon (23%), followed by gastrointestinal cancer (14%), and pancreatic cancer (11%).	"This retrospective study systematically evaluated the feasibility of physical exercise or therapy in terminally ill cancer patients." p. 1261	Physical exercise and/or physical therapy	"Physical exercise/ physical therapy were feasible in >90% of terminally ill cancer patients to whom physical exercise/physical therapy had been offered." p. 1261
Jensen et al <sup>45</sup>	<ul style="list-style-type: none"> <li>University Medical Center Eppendorf, Hamburg, Germany</li> <li>University Medical Center, Leipzig, Germany</li> <li>German Sport University of Cologne, Cologne, Germany</li> </ul>	Study protocol	N/A	Patients will be recruited who have advanced lung cancer	"The aims of the study protocol are to investigate different adapted physical training programs in patients with advanced lung cancer undergoing palliative chemo- or radiotherapy." p. 120	Group 1: aerobic exercise, Group 2: resistance training, Group 3: control (no specific exercise training)	"The results of this study will offer an overview over possible effects of specific training interventions on health related quality of life, physical and psychological symptoms, and on the efficacy of oncologic treatment." p. 120
Johnson et al <sup>46</sup>	<ul style="list-style-type: none"> <li>University of Hull, Hull, UK</li> <li>University of York, York, UK</li> <li>Dove House Hospice, Hull, UK</li> <li>Humber NHS Foundation Trust, Willerby, UK</li> <li>Castle Hill Hospital, Hull, UK</li> <li>University of Cambridge, Cambridge, UK</li> </ul>	Multi-centre randomized controlled non-blinded parallel arm trial	N=156 patients	Adults with intra-thoracic malignancy	"The present study aims to test whether three sessions are better than one for breathlessness in this population." p.1	Group 1: 3 sessions of breathing technique training, group 2: 1 session of breathing technique training	"There was no evidence that three sessions conferred additional benefits, including cost-effectiveness, over one. A single session of breathing training seems appropriate and minimises patient burden." p.1
Kumar et al <sup>47</sup>	<ul style="list-style-type: none"> <li>University of Pennsylvania, Philadelphia, PA, USA</li> </ul>	Cross-sectional	N=313	Patients with a diagnosis of breast, lung, or gastrointestinal cancer	"The goals of this study were to: 1) measure the rate of utilization of supportive and palliative care services (SPCS) at an urban, academic medical cancer center; 2) identify factors related to use of SPCS; and 3) identify and describe patient reported barriers to access to SPCS." p.924	N/A	"Approximately half of these patients had not accessed supportive and palliative care services since cancer diagnosis and cite lack of awareness and physician nonreferral as barriers." p. 923
Leppert et al <sup>48</sup>	<ul style="list-style-type: none"> <li>Poznan University of Medical Sciences, Poznan, Poland</li> <li>Gdansk Medical University, Gdansk, Poland</li> <li>Home Hospice for Adults and Children, Poznan, Poland</li> <li>Wroclaw University of Medical Sciences, Wroclaw, Poland</li> </ul>	Prospective observational study	N=78 patients	Adult patients with advanced lung cancer	"The aim of the study was to evaluate the symptom intensity and quality of life in patients treated at home and in those who stayed at a palliative care unit during the follow-up." p.379	N/A	"Quality of life deteriorated with few differences between home and the palliative care unit patients." p. 379



Maddocks et al <sup>49</sup>	<ul style="list-style-type: none"> <li>• Kings College London, London, UK</li> <li>• University of Nottingham, Nottingham, UK</li> <li>• King's Mill Hospital, Sutton in Ashfield, UK</li> <li>• Cardiff University, Cardiff, UK</li> </ul>	Randomized controlled trial	N=49 patients	Patients with advanced non-small cell lung cancer	"The primary aim of this study was to determine the acceptability of neuromuscular electrical stimulation of the quadriceps to patients with non-small cell lung cancer used alongside palliative chemotherapy." p.1	Neuromuscular electrical stimulation of the quadriceps or control group	"Neuromuscular electrical stimulation is not acceptable in this setting, nor was there a suggestion of benefit." p.1
Nwosu et al <sup>50</sup>	<ul style="list-style-type: none"> <li>• University of Liverpool, Liverpool, UK</li> <li>• Woodlands Hospice Charity Trust, Liverpool, UK</li> <li>• Aintree University Hospitals NHS Foundation Trust, Liverpool, UK</li> </ul>	Cross-sectional	N=59 healthcare professionals	Respondents' perceptions of rehabilitation interventions for patients with lung cancer	"This study aims to explore the perceptions of palliative care and respiratory multidisciplinary team members about the role of rehabilitation for lung cancer patients." p.3247	N/A	"Long waiting times and lack of knowledge of services are among several factors that may prevent lung cancer patients being offered rehabilitation." p.3247
<b>Articles Focussed on Patients With Interstitial Lung Disease Diagnosis</b>							
Bajwah et al <sup>51</sup>	<ul style="list-style-type: none"> <li>• Royal Marsden and Royal Brompton NHS Foundation Trusts, London, UK</li> <li>• King's College London, London, UK</li> <li>• Imperial College, London, UK</li> </ul>	Systematic review	N=34 articles	Fibrotic interstitial lung disease	"This review aims to evaluate the evidence for the use of interventions in improving dyspnoea, other symptoms and quality of life." p.867	N/A	"There is strong evidence for the use of pulmonary rehabilitation and pirfenidone to improve 6MWD and moderate evidence for the use of sildenafil and pulmonary rehabilitation to improve QoL." p. 867
Bajwah et al <sup>52</sup>	<ul style="list-style-type: none"> <li>• King's College London, London, UK</li> <li>• Imperial College, London, UK</li> <li>• Royal Marsden and Royal Brompton NHS Foundation Trusts, London, UK</li> </ul>	Qualitative	Total participants N=18: n=8 patients; n=4 informal caregivers; n=6 healthcare professionals	Patients with fibrotic interstitial lung disease, their informal caregivers and their health care professionals	"This study aims to explore the specialist palliative care needs of people living with end-stage progressive idiopathic fibrotic interstitial lung disease." p.869	N/A	"Education and guidance of appropriate palliative care interventions to improve symptom control are needed." p. 869
Bajwah et al <sup>53</sup>	<ul style="list-style-type: none"> <li>• Royal Marsden and Royal Brompton NHS Foundation Trusts, London, UK</li> <li>• King's College London, London, UK</li> <li>• Imperial College, London, UK</li> </ul>	Randomized controlled phase II and feasibility trial	N=53 patients	Patients with a clinical diagnosis of advanced idiopathic fibrotic lung disease	"To obtain preliminary information on the impact of a case conference intervention delivered in the home (Hospital2Home) on palliative care concerns of patients and their carers, and to evaluate feasibility and acceptability." p.830	Fast tracked to Hospital2Home (collaboration between patients and health care professionals) or wait-list group	"Community case conferences improve palliative symptoms and quality of life after 4 weeks. Hospital2Home for the most part is both feasible and acceptable." p. 830
Danoff et al <sup>54</sup>	<ul style="list-style-type: none"> <li>• Johns Hopkins University School of Medicine, Baltimore, MD, USA</li> </ul>	Review	N/A	Idiopathic pulmonary fibrosis	"This review will focus on aspects of nonpharmacologic interventions including palliative care, mental healthcare, pulmonary rehabilitation, support groups, oxygen use, and vaccinations, as all are available therapies that might allow patients with idiopathic pulmonary fibrosis to optimize their quality of life." p.481	N/A	"Incorporating supportive and palliative measures in the care of patients with IPF may improve both quality of life and survival, but far more research is needed in this fledgling field." p. 480
Garibaldi et al <sup>55</sup>	<ul style="list-style-type: none"> <li>• Johns Hopkins University School of Medicine, Baltimore, MD, USA</li> </ul>	Review	N/A	Idiopathic interstitial pneumonia	"This article will explore common symptoms experienced by patients with Idiopathic interstitial pneumonia and focus on 'symptom-based' therapies and interventions that may be effective." p.1357-8	N/A	"Patient education and self-management are key components of formulating treatment plans and establishing goals of care. Palliative care is not limited to the end-of-life and should begin at the time of diagnosis." p. 1363

Gulati et al <sup>56</sup>	<ul style="list-style-type: none"> <li>Yale University School of Medicine, New Haven, CT, USA</li> </ul>	Review	N/A	Connective tissue disease/ interstitial lung disease	<p>"This article addresses supportive measures such as supplemental oxygen and pulmonary rehabilitation. Issues related to quality of life, sleep disturbances, and identification of mood disorders are discussed." p. 274</p>	N/A	<p>"In managing patients with advanced connective tissue associated pulmonary disorders, clinicians may neglect to address the daily challenges confronting their patients and affecting their quality of life and general health status." p. 279</p>
Holland et al <sup>57</sup>	<ul style="list-style-type: none"> <li>Alfred Health, Melbourne, Australia</li> <li>La Trobe University, Melbourne, Australia</li> <li>Austin Health, Heidelberg, Australia</li> <li>Monash University, Melbourne, Australia</li> </ul>	Qualitative	n=18 patients; n=14 clinicians	Patients with interstitial lung disease and clinicians who care for people with interstitial lung disease	<p>"This study explored the perspectives of patients and interstitial lung disease clinicians regarding the educational content of pulmonary rehabilitation for interstitial lung disease." p. 93</p>	N/A	<p>"We conclude that people with ILD have specific educational needs that may not be met in the current pulmonary rehabilitation format." p. 93</p>
Lewis et al <sup>58</sup>	<ul style="list-style-type: none"> <li>Birmingham City University, Birmingham, England</li> <li>Glenfield General Hospital, Leicester, England</li> </ul>	Review	N/A	Idiopathic pulmonary fibrosis	<p>"This article reviews what is known about idiopathic pulmonary fibrosis, discussing diagnosis, prognostication dilemmas, the role of pulmonary rehabilitation, and best supportive care." p. 331</p>	N/A	<p>"Current pulmonary rehabilitation programmes may be limited in improving lung function but may improve patients' functional capacity and ability to cope with activities of daily living as well as providing support. The management of key symptoms such as dyspnoea and cough is largely based on clinical practice in other chronic diseases such as COPD, and more research is needed." p. 336</p>
<b>Articles Focussed on Patients With A Huntington's Disease</b>							
Reyes et al <sup>59</sup>	<ul style="list-style-type: none"> <li>Edith Cowan University, Joondalup, WA, Australia</li> <li>University of Western Australia, Crawley, WA, Australia</li> </ul>	Pilot randomized controlled trial	N=18 patients	Patients with manifest Huntington's disease	<p>"To examine the effects of 4-month of respiratory muscle training on pulmonary and swallowing function, exercise capacity and dyspnoea in manifest patients with Huntington's disease." p. 961</p>	Increased resistance during respiratory muscle training or respiratory muscle training with no increase in resistance	<p>"A home-based respiratory muscle training program appeared to be beneficial to improve pulmonary function in manifest Huntington's disease patients but provided small effects on swallowing function, dyspnoea and exercise capacity." p. 961</p>
<b>Articles Focussed on Patients With A Multiple Disease Diagnosis</b>							
Barawid et al <sup>5</sup>	<ul style="list-style-type: none"> <li>University of California Irvine Medical Center, Orange, CA, USA</li> </ul>	Review	N/A	Cancer, COPD, congestive heart failure, neurodegenerative disorders	<p>"This article describes the role of rehabilitation modalities in palliative care and reviews the evidence for the benefit of rehabilitative care in the common, major diagnoses. The following sections will focus on major diagnoses; cancer, COPD, CHF, and neurodegenerative disorders." p.35</p>	N/A	<p>"Regardless of the diagnosis, the goal for all palliative care patients should be to maintain their QOL and maximize their function in accordance with the patient and family's priorities. This narrative review article has provided evidence to support that rehabilitation should be part of the palliative care to achieve that goal." p. 41</p>
Bausewein et al <sup>11</sup>	<ul style="list-style-type: none"> <li>Munich University Hospital, Munich, Germany</li> <li>University Hospital Cologne, Cologne, Germany</li> </ul>	Review	N/A	COPD, cancer	<p>"This article is intended to acquaint the reader with: the need for standardized assessment of shortness of breath and cough in patients with advanced disease, the non-pharmacological treatment options for shortness of breath and cough, the most important medications for the treatment of shortness of breath and cough, the role of oxygen in the treatment of shortness of breath and its proper, judicious use." p.564</p>	N/A	<p>"In most patients, shortness of breath and cough can be relieved by a series of therapeutic measures." p. 563</p>

Burge et al <sup>30</sup>	<ul style="list-style-type: none"> <li>La Trobe University, Melbourne, VIC, Australia</li> <li>University of Melbourne, Melbourne, VIC, Australia</li> <li>Alfred Health, Melbourne, VIC, Australia</li> <li>Monash University, Melbourne, VIC, Australia</li> </ul>	Prospective qualitative study	N=67 patients	Majority of patients had COPD (72%), remaining patients had idiopathic pulmonary fibrosis, or other lung conditions	"To evaluate the introduction of a structured group advance care planning information session from the perspective of participants in pulmonary rehabilitation and maintenance programmes." p. 508	N/A	"Participants in our pulmonary rehabilitation and maintenance programmes value the opportunity to participate in a structured, group-based advance care planning session" p. 508
Farquhar et al <sup>31</sup>	<ul style="list-style-type: none"> <li>University of Cambridge, Cambridge, UK</li> <li>Imperial College London, London, UK</li> <li>King's College London, London, UK</li> <li>University of Manchester, Manchester, UK</li> </ul>	Single-centre phase III fast-track single-blind mixed method randomized controlled trial	N=87 patients	Majority of patients had COPD (80%), remaining patients had "other" non-malignant lung disease	To evaluate the effectiveness of a breathlessness intervention service	Breathlessness Intervention Service vs. standard care	"Breathlessness intervention service had a statistically non-significant effect for patients with non-malignant conditions, and slightly increased service costs, but had a qualitatively positive impact consistent with findings for advanced cancer." p.1
Higginson et al <sup>32</sup>	<ul style="list-style-type: none"> <li>King's College London, London, UK</li> <li>Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK</li> <li>University of Amsterdam, Amsterdam, Netherlands</li> <li>Munich University Hospital, Munich, Germany</li> </ul>	Single-blind randomized controlled trial	N=105 patients	Majority of patients had COPD (54%), and the remaining patients had cancer (20%), interstitial lung disease (18%), or other (8%)	"We assessed the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness." p.979	Breathlessness support service	"... findings provide robust evidence to support the early integration of palliative care for patients with diseases other than cancer and breathlessness as well as those with cancer." p. 979
Malcolm et al <sup>33</sup>	<ul style="list-style-type: none"> <li>St Christopher's Hospice, London, UK</li> <li>St George's University of London and Kingston University, London, UK</li> <li>King's College London, London, UK</li> </ul>	Qualitative, phenomenology	N=9 patients	Majority of patients had cancer (56%), the remaining patients had end-stage lung disease (33%), or "other"	"The aim of this study was to explore patients' experiences of participating in group exercise classes in a hospice setting." p.1	Participation in a group exercise class	"This study highlights the positive experiences and value of group exercise classes to groups of people with diverse cancer and non-cancer conditions." p.1
Reilly et al <sup>34</sup>	<ul style="list-style-type: none"> <li>King's College London, London, UK</li> <li>Munich University Hospital, Munich, Germany</li> </ul>	Cross-sectional	N=25 patients	Majority of patients had COPD (56%), the remaining patients had cancer (24%), idiopathic lung disease (16%), or other (4%)	"This study aimed to describe patients' experiences of the breathlessness support service and identify the aspects valued." p.313	Breathlessness support service	"Patients' satisfaction with the breathlessness support service was high, and identified as important to this was a combination of personalised care, nature of staff, education and empowerment, and use of specific interventions." p. 313
Rodgers et al <sup>35</sup>	<ul style="list-style-type: none"> <li>University of Alberta, Edmonton, AB, Canada</li> </ul>	Randomized controlled trial	N=40 patients	Majority of patients had COPD (63%), followed by asthma (27%), or other lung conditions (10%)	"This study compared the long-term effects of exercise and social implementation intentions interventions on objectively measured physical activity." p.480	Exercise implementation intervention vs. social implementation intervention	"Improvements attained by the exercise group during the intervention were not maintained 6-months following rehabilitation. Implementation intentions targeting physical activity appear to have positive short term effects on physical activity, although the long term effects are less consistent" p. 480
Swan et al <sup>36</sup>	<ul style="list-style-type: none"> <li>University of Hull, Hull, UK</li> <li>University of Cambridge, Cambridge, UK</li> </ul>	Review	N/A	COPD, cancer	"Therefore, it is timely and relevant to review the research available for the efficacy and appropriateness of facial or nasal airflow." p.206	N/A	"The hand-held fan should be considered as one of the first interventions to try in management plans for patients who present with mild hypoxaemia or normoxaemia and chronic refractory breathlessness at rest or on minimal exertion" p. 206

Weingaertne et al <sup>37</sup>	<ul style="list-style-type: none"> <li>• University Hospital of Cologne, Cologne, Germany</li> <li>• Protestant Hospital Oldenburg, Oldenburg, Germany</li> <li>• University Hospital Munich, Munich, Germany</li> <li>• King's College London, London, UK</li> </ul>	Prospective, cohort study	N=82 patients (n=50 patients with COPD; n=32 patients with lung cancer)	Majority of patients had COPD (61%), the remaining had lung cancer	"To describe and compare the courses of refractory breathlessness, functional status, distress, and palliative care needs in patients with advanced chronic COPD or lung cancer over time." p.569	N/A	"The palliative care needs of patients with advanced chronic obstructive pulmonary disease are comparable with lung cancer patients, and breathlessness severity and distress are even higher." p. 569
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A range of study designs were employed including randomized controlled trials, interventional studies, observational studies, and qualitative studies primarily involving semi-structured interviews, surveys, or questionnaires. The majority of studies were interventional (n=15) or mixed methods/qualitative (n=15), with the majority of the studies focussed on populations with COPD (n=17) and cancer (n=6). There were a number of review articles (n=14), with equal focus on COPD (n=5) and interstitial lung disease (n=5). The remaining study designs were randomized controlled trials (n=5) with the majority of studies coming from a patient population of multi-disease diagnoses (n=3), observational studies (n=5), case report (n=1), and retrospective feasibility analysis (n=1). The article on Huntington's disease was a pilot randomized controlled trial. Most articles originated in the United Kingdom (n=15), or the USA (n=13 articles), with other countries contributing as well; Canada (n=5), Germany (n=4), Australia (n=4), The Netherlands (n=3), and other countries (n=4). The remaining studies had contributions from multiple countries (n=8).

**Chronic Obstructive Pulmonary Disease (COPD)**

COPD is a chronic progressive terminal disease, that although can be treated, cannot be cured. The trajectory of the disease is usually a progressive decline with periodic acute exacerbations. Each exacerbation that leads to hospitalization increases the risk of death, with mortality rates as high as 22% at 12 months post-hospitalization.<sup>22</sup> Pulmonary rehabilitation therefore has a role to play in preventing exacerbations by trying to prevent deterioration and building up resistance. In later stages of COPD, patients often experience dyspnea, decreased ability to carry out activities of daily living, anxiety and depression, pain, and insomnia. Most patients with COPD report dyspnea as their most distressing symptom.<sup>10</sup> Of patients with severe COPD, the prevalence of depression ranges from 37% to 71% and the prevalence of anxiety ranges from 50% to 75%.<sup>27</sup> In one study, about 13% of patients with severe COPD reported a loss of dignity that was correlated with anxiety and depression but not lung function.<sup>25</sup> Community dwelling palliative home care patients experiencing dyspnea were more likely to show overall signs of distress.<sup>2</sup> Dyspnea appears to be directly related to anxiety and depression, because by improving symptoms of shortness of breath, rates of anxiety and depression also improved in the same patient.<sup>10</sup> Patients therefore opted to treat dyspnea and anxiety/depression together as opposed to separately.<sup>10</sup> Pulmonary rehabilitation and palliative care can come together to address the physical dete-

rioration of patients with COPD to prevent exacerbations. Focus can also be put on the psychological well-being of the patient to improve depression and anxiety as both contribute to functional decline in patients with COPD.

Traditionally, palliative care has most often been associated with patients suffering with terminal cancer, and less so on patients with chronic illnesses such as COPD. This may be due to the fact that the trajectory to death is often less clear in chronic illnesses as compared to terminal cancer.<sup>60</sup> Therefore, referral to pulmonary rehabilitation and palliative care may be given too late or not at all for patients with chronic illness. Patients with COPD have been found to have a worse QoL as compared to patients with cancer but may survive 5 times as long on average.<sup>10,16</sup> Patients with COPD also report higher perceived breathlessness and report experiencing severe to very severe breathlessness over the past 24 hours at a rate 3 times higher as compared to patients with lung cancer receiving palliative care.<sup>37</sup> Severity of perceived breathlessness was also correlated with more palliative care needs in persons with COPD but not for those with lung cancer.<sup>37</sup> It is therefore ideal to refer patients with COPD to pulmonary rehabilitation and palliative care as soon as they become symptomatic. Palliative care and pulmonary rehabilitation should be implemented earlier on in COPD disease progression and programs should be tailored to the specific needs of persons with this disease as these needs are different from those with cancer, such as longer survival, worse QoL, and more palliative care needs.<sup>10,16</sup> In doing so, this may help to alleviate dyspnea, anxiety, and depression and therefore improve QoL at end-of-life.

**Benefits of Pulmonary Rehabilitation for Patients with COPD in Palliative Care**

Pulmonary rehabilitation does not address the underlying pathology of COPD, but works to improve the impairment in function and assist with symptom management.<sup>5</sup> Exercise is at the core of a pulmonary rehabilitation program and it works to recondition the legs and other peripheral muscles in the body to use oxygen more efficiently, therefore requiring less.<sup>27</sup> If patients are not able to perform physical exercise, such as in the later stages of their disease, neuromuscular electric stimulation has been shown to be effective. Stimulating leg muscles in order to increase strength in patients with COPD showed improvements in shortness of breath measurements. The beneficial effect is only seen after 4-6 weeks of regular stimulation (3-5 sessions



per week) so may not be feasible in very end-of-life care.<sup>1</sup>

Pulmonary rehabilitation includes: teaching breathing exercises, educating patients on the importance of smoking cessation, as well as highlighting how to recognize an oncoming dyspnea attack and equipping patients with methods on how to control it. A Taiwanese randomized clinical study followed patients with COPD over the course of a 12-week pulmonary rehabilitation program.<sup>17</sup> It showed that patients in the rehabilitation arm of the study improved in lung function, distance on the 6-minute walk test, and QoL measures. Programs as short as 4 weeks have also been shown to improve health related QoL and functional exercise capacity in patients with COPD.<sup>5</sup> Pulmonary rehabilitation is under-utilized in palliative care possibly due to the perceived lack of cost-benefit ratio, due to limited prognoses, as well as the inaccessibility of the out-patient based clinics for this patient population.<sup>5</sup> For palliative care patients that may not be well enough to attend an out-patient based 12-week pulmonary rehabilitation program, a Breathlessness Support Service (BSS) with limited out-patient appointments may be an alternative option. In a randomized, single-blinded study, patients with COPD were assigned to either the BSS or care as usual.<sup>32</sup> The BSS integrated many disciplines including both palliative care and pulmonary rehabilitation. The service consisted of 3 stages. The first stage is an outpatient clinic appointment with respiratory medicine and palliative care physicians. The second stage is a home assessment by a physiotherapist/occupational therapist done 2-3 weeks after the initial visit. The final stage, completed 4 weeks after the initial visit, is a second clinic appointment with a palliative care specialist. Following the 4 weeks, patients in the Breathlessness Support Service reported better mastery of breathing and also showed a longer survival rate for 6 months after randomization.<sup>32</sup> In a follow-up to this study, patients who used the Breathlessness Support Service were asked to fill out questionnaires.<sup>34</sup> A total of 84% of participants who filled out the survey said they found the service useful, and that it helped them manage their breathlessness as well as mood and mobility. A similar service also from the United Kingdom, termed the Breathlessness Intervention Service (BIS), was evaluated to determine if it could influence patient's reports of distress from breathlessness.<sup>31</sup> The BIS is a multidisciplinary intervention that educates patients on breathing techniques, secretion clearance, mindfulness and relaxation, exercise, and energy conservation. Although the results were non-significant for the primary outcome of patient distress due to breathlessness at 4 weeks, 92% of patients reported it had made a positive impact on their lives.<sup>31</sup>

Pulmonary rehabilitation efforts do not need to be complex or expensive. One study showed that placing a hand held fan in front of a patient's face and nose can improve shortness of breath in some patients.<sup>1,36</sup> Another study suggested that pursed-lip breathing can be effective in helping with breathlessness.<sup>10</sup> Other unique avenues for rehabilitation, including therapeutic singing have been tried.<sup>13</sup> One feasibility study involving therapeutic singing reported there were no improvements in health

related QoL, exercise capacity, or perceptions of illness at the end of the singing trial, although the singing intervention was received enthusiastically by patients.

Since access to hospital-based pulmonary rehabilitation programs can be a barrier to use, newer technologies such as telerehabilitation can be implemented to reach patients receiving palliative care, whether it be home based or located in a facility. The feasibility of this was recently tested in a pre-experimental study on the effectiveness, satisfaction, and adherence to a telerehabilitation intervention.<sup>20</sup> Patients with moderate to very severe COPD participated in 15 in-home teletreatment sessions. Overall this resulted in improvements in the 6-minute walk test as well as in dyspnea, fatigue, and emotion.

Another pilot study using telehealth technology to reach patients trialed teaching pursed-lip breathing using Skype.<sup>19</sup> The study demonstrated that there was an improvement in QoL, and further showed that as dyspnea worsens, pursed lip breathing may become more effective.<sup>19</sup> This intervention may therefore be useful for palliative care patients that are suffering from very severe COPD and who may be house or hospice-bound.

Traditionally, patient improvements in rehabilitation have been evaluated for functional independence such as the 6 minute walk test. Newer studies addressing pulmonary rehabilitation in palliative care patients should consider alternative methods of monitoring progress as patients may not have functional independence at baseline. A comprehensive standardized assessment instrument such as the interRAI Palliative Care Assessment instrument,<sup>61</sup> and more specifically the dyspnea Clinical Assessment Protocol (CAPs)<sup>62</sup> might be better suited to monitor client progress in this palliative patient population.

#### **Motivation for Patients to Complete Pulmonary Rehabilitation**

Motivating patients to engage in and complete pulmonary rehabilitation interventions can be challenging. Up to 50% of patients with COPD enrolled in a pulmonary rehabilitation program did not attend any sessions, despite convincing evidence for the benefit of rehabilitation in this patient population.<sup>21</sup> Studies have shown that patients with COPD that lead active lives before developing COPD tended to be more motivated to do pulmonary rehabilitation whereas patients that were more sedentary before developing COPD did not increase activities because of starting a pulmonary rehabilitation program.<sup>26</sup> Risk factors for dropout or nonadherence to pulmonary rehabilitation include depressive and anxiety symptoms.<sup>21</sup> The development of depressive symptoms in patients with severe to very severe COPD also indicates a higher risk of dying at 12 months.<sup>60</sup> Of note, pulmonary rehabilitation offers the most benefits to patients who score highest in anxiety and depression before starting rehabilitation, as well as patients who have not adapted (physically or psychologically) well to the disease.<sup>23,27</sup> Unfortunately, as noted above, these are also the same patients whom are least likely to finish rehabilita-



tion even though they would derive the most benefit. Noticing a change in baseline, or the development of anxiety and depression, should warrant the involvement of palliative care and pulmonary rehabilitation in the patient's care if they are not already.

Simply enrolling patients in pulmonary rehabilitation programs and having them attend however, may not be sufficient. In fact, patient's illness perspectives before starting pulmonary rehabilitation have been linked to less favourable outcomes post-rehabilitation.<sup>29</sup> Patients create their own ideas about the identity of the disease, consequences, and controllability of it. As an illustrative example, a maladaptive belief such as *"my disease will worsen regardless of what I do and I deserve to have it"* could result in increased levels of anxiety and depression, and may lead to less motivation to attend or complete a pulmonary rehabilitation intervention. The disease course of COPD has been shown to have 4 psychological stages associated with it including: denial, resistance, sorrow, and acceptance.<sup>9</sup> Placing patients into pulmonary rehabilitation before they reach the acceptance phase may not provide functional improvements for that patient. In fact, patients with severe to very severe COPD, who began pulmonary rehabilitation with negative beliefs about the impact of their disease and showed higher levels of fear, anxiety, and distress, saw fewer improvements in exercise capacity and less distance increases in the 6-minute walk test.<sup>29</sup> It is therefore important to identify maladaptive beliefs and misconceptions early on in treatment and work towards changing these beliefs to facilitate opportunity for the best possible outcome. Options to achieve this include: screening patients for which phase of the "grief process" they are in, and then combining pulmonary rehabilitation with collaborative self-management, and mindfulness based therapy. The Acceptance of Disease and Impairments Questionnaire (ADIQ) can be administered to patients before they begin, so that rehabilitation can be tailored to where on the spectrum they fall (denial, resistance, sorrow, or acceptance).<sup>9</sup> Collaborative self-management is a healthcare intervention which places patient self-care efforts as well as beliefs at the core of treatment. Pulmonary rehabilitation teaches patients with COPD what they can do, whereas collaborative self-management provides the "will do".

Collaborative self-management attempts to change unhealthy beliefs and then maintain healthy behaviours and mindsets.<sup>24</sup> Often, reported symptoms of the disease are not in line with expected results from physiological test results, which may result from poorly adapted beliefs and viewpoints of the disease.<sup>23</sup> One study was able to put moderate COPD sufferers into two categories: patients who reported low impact of disease on health status and patients who reported high impact of disease on health status despite both populations having similar physiological impairments.<sup>23</sup> Although, both patient populations improved with pulmonary rehabilitation, the patients that subjectively experienced a higher impact of disease on their overall health status benefited most from a pulmonary rehabilitation program.<sup>23</sup> Changing patients' beliefs and understanding of their disease is

therefore an important part of rehabilitation. Another therapy to assist patients is mindfulness based therapy. An 8-week trial of mindfulness based therapy was carried out to evaluate patient's awareness of breathlessness, activity levels, anxiety or low-mood after the trial.<sup>18</sup> As opposed to pulmonary rehabilitation which focuses on how to control the breath, mindfulness-based cognitive therapy focuses on noticing the breath and "turning toward difficulty." An interesting observation from this study was that participants described "stepping back" from the breathlessness-fear cycle and creating a "safe-space" in which to choose an appropriate response to their symptoms. Instead of allowing fear and anxiety to drive their thought cycle during a dyspnea attack (*"I cannot breathe! I am going to die"*), patients took control of the situation and thought through the best course of action.<sup>18</sup> This led to some participants implementing pulmonary rehabilitation advice for the first time. Pulmonary rehabilitation techniques were not taught during the study, so participants were linking what they were taught in pulmonary rehabilitation with mindfulness in a way that worked for them. Another study showed most patients with COPD were willing to try mindfulness based techniques if they were taught in a short session in pulmonary rehabilitation by an enthusiastic knowledgeable trainer.<sup>14</sup> Although, breathing techniques are taught in pulmonary rehabilitation, re-enforcing those techniques and empowering patients to gain control over their breathlessness with mindfulness-based therapy appears to be a promising avenue.

#### Barriers to Pulmonary Rehabilitation in Palliative Care

There are many barriers to patients accessing pulmonary rehabilitation and palliative care in the context of COPD. Examples include: patients attributing their symptoms to a natural case of "getting older" and therefore do not seek help, a patient holds a belief that there are no treatments available to improve their situation, or a patient may have guilt for causing their condition, fear they will be judged and blamed for their condition and therefore do not deserve or seek treatment.<sup>4,15,16</sup> One study showed that patients with COPD admitted to having dyspnea severe enough to disrupt their lives and accepted this as a normal part of life rather than as a consequence of the disease.<sup>4</sup> Patients also identified distance as a barrier to participating in pulmonary rehabilitation including transportation to and from and the associated cost in getting to the hospital.<sup>21</sup> Another barrier appears to be a lack of education in the general population as to what COPD is and the time course of the disease. When interviewing patients and health care professionals in the United Kingdom, there was agreement between the two groups about a lack of knowledge about COPD and the trajectory of the disease at the national, local, and individual level.<sup>11</sup> Another study indicated that poor communication among health care professionals and with patients as to what pulmonary rehabilitation is and how it can benefit patients, frequently occurs.<sup>12,26</sup> Patients complained that health care providers were not taking the time to explain their condition and offer solutions. Contributing to this problem was that some patients felt their general practitioners had lim-

ited knowledge about pulmonary rehabilitation and they were therefore not told of the benefits of rehabilitation or simply not referred to these programs at all.<sup>12,21,26</sup> One study found only 3-16% of eligible patients were referred for pulmonary rehabilitation.<sup>12</sup> Even the referring physician's attitude toward pulmonary rehabilitation influences whether a patient will attend or not.<sup>21</sup> Healthcare professionals need to improve tailoring of education to meet the individual needs of their patients regarding COPD and its trajectory, referring patients to and discussing benefits of pulmonary rehabilitation, and involving palliative care early on in their patient's treatments so that patients can derive maximum benefit.

### Advanced Directives Introduced in Pulmonary Rehabilitation

The unpredictable course of COPD and the lack of education/understanding patients have regarding the debilitating course of the disease, means that end-of-life directives and access to palliative care is often started too late. Despite this, patients report that their physicians are not very willing to discuss the topic of advanced directives.<sup>16</sup> Invariably, these decisions are often left to a time late in the disease trajectory when patients may not be well enough to participate in the decision making process. This is especially true for patients with COPD. In one study only 31% of patients with advanced COPD correctly estimated that their life expectancy was less than 1 year, in the month before their death.<sup>16</sup> Pulmonary rehabilitation may be a well-suited environment for patients to be educated on and discuss end-of-life directives. In a study of 67 participants with a range of chronic lung diseases, the majority of participants felt pulmonary rehabilitation was an appropriate setting to discuss advance care planning.<sup>30</sup> The participants also accepted the group format and were happy to receive the information from a non-medical facilitator.<sup>30</sup> Since some patients may receive pulmonary rehabilitation earlier on in the disease trajectory before they encounter palliative care, rehabilitation may be an appropriate setting for patients to be introduced to and discuss advanced directives before they functionally decline.

### Geriatric Rehabilitation for COPD

Geriatric rehabilitation has emerged as a new field. Although, the rehabilitation approach is the same as in pulmonary rehabilitation (multi-disciplinary and patient-centred), the patient population it targets is aged. Older adult patients referred to geriatric rehabilitation often have many co-morbidities and differ in their rehabilitation goals as compared to younger, healthier, or more mobile patients. Geriatric care is primarily for patients who are usually more advanced in the disease trajectory and who may be excluded from other pulmonary rehabilitation programs due to the patients advanced age and disease stage. A study has shown that elderly patients (mean age=70 years) who refused to participate in a pulmonary rehabilitation program after a COPD exacerbation cited non-interest (39%) or felt "too sick or frail" to participate (24%) as the two main reasons for declining pulmo-

nary rehabilitation.<sup>8</sup> To counter this perspective, a geriatric rehabilitation study was performed on patients (average age=68.9 years) with severe and very severe COPD. The results showed that patients improved on the 6 minute walk test (208 m ( $\pm$ 119m) to 274 m ( $\pm$ 122m)), on activities of daily living (Barthel Index), and less patients were underweight when the study concluded.<sup>28</sup> This suggests a pulmonary rehabilitation program tailored specifically to elderly patients with severe/very severe COPD is still beneficial. As mentioned above in the "Barriers to Pulmonary Rehabilitation" section, communication between healthcare providers and patients' needs to be strengthened so that patients can see and experience the value and importance of participating in pulmonary rehabilitation. Healthcare providers should also be realistic about the outcomes of pulmonary rehabilitation, as a study has shown that patient expectations ("to be cured of the disease") can often be confused with physician goals ("to improve walking distance").<sup>26</sup> When communicated clearly to patients, pulmonary rehabilitation programs and specifically geriatric rehabilitation programs, can help focus a patient to set realistic goals so that patients can maintain activities that are important to them.<sup>26,28</sup> Information should also be given to the patient that regardless of how advanced their disease is, there is potential for rehabilitation to assist with improving health status and functional capacity.<sup>28</sup>

### Cancer

Rehabilitation for persons with advanced cancer has been shown to be feasible and beneficial.<sup>39,40,42,44</sup> Even in later stages of palliative care, patients wish to maintain some level of independence and to be physically strong.<sup>40</sup> Disability and loss of independence can occur in this population due to prolonged bed rest, resultant deconditioning, and musculoskeletal complications of treatment.<sup>5</sup> Patients also expressed a need for help with tiredness and lack of energy.<sup>44</sup> Rehabilitation can address these issues and help patients to maintain some degree of function. A home exercise program adapted to patients with stage IV lung and colorectal cancer over 8-weeks showed improved mobility, fatigue, and sleep quality compared to usual care.<sup>39</sup> Patients also commented that physical therapy was important to them and provided comfort as well as increased capabilities of carrying out daily routines and offering hope.<sup>40</sup> Although, a possible benefit for neuromuscular stimulation was reported for patients with COPD, there does not appear to be any functional benefit for patients with lung cancer, although changes in dyspnea were not studied.<sup>49</sup>

A study showed that implementing an exercise or therapy program for terminally ill cancer patients (primarily lung cancer) was feasible in >90% of cases.<sup>44</sup> Fifty-four percent of patients could perform physical exercise whereas, the remaining patients experienced relaxation therapy or breathing exercises. Authors reported that a study looking at the outcomes of aerobic exercise, resistance training, or a control group in patients with metastatic lung cancer is being planned.<sup>45</sup> This study could

provide insight into the type of exercise advanced lung cancer patients would most benefit from to allow tailored rehabilitation programs to be designed.

Patients with lung cancer experience a respiratory symptom cluster that consists of breathlessness, cough, and fatigue that is often not relieved from pharmacological treatment alone.<sup>41</sup> Usually, only breathlessness is targeted for treatment, leaving the other symptoms present. When patients with lung cancer were asked what were important characteristics of non-pharmacological interventions to manage their symptoms they mentioned the importance of seeing benefits in the short-term, easy/simple exercises they could fit into their routine, the timing of suggested interventions, and the venue of where the intervention would be given. Due to differing opinions in this study, it would be helpful if there was an adaptable rehabilitation program that could cater to the specific needs of individual patients and their preferences.<sup>41</sup> Patients also mentioned they would not use interventions that they felt were not relevant to them. It is important therefore, that the education side of pulmonary rehabilitation is continually and consistently given to patients throughout their program, re-enforcing the benefits of rehabilitation. A BIS in the United Kingdom seemed to implement this individualized intervention program for patients with advanced cancer (mostly lung).<sup>42</sup> The service was provided for 2 weeks and usually consisted of consultations in the patient's home. Integrated services educated patients, provided resources, and connected them with palliative care. If deemed necessary, patients could be referred to other services (including further rehabilitation). Patients reported managing their breathlessness better, and feeling less anxious or fearful. Even simpler interventions may assist patients with intrathoracic cancer.<sup>46</sup> The teaching of breathing management techniques were delivered over a one-hour long session or over three one-hour long sessions. In terms of the primary outcome, patient reported intensity of worst-breathlessness over the past 24 hours was the same in both groups.<sup>46</sup> Suggesting even a brief pulmonary rehabilitation counseling session may prove beneficial and cost-effective, especially when patients may have a limited prognosis.

#### Barriers to Pulmonary Rehabilitation in Patients with Cancer

Similar to patients with COPD, patients with cancer experience many barriers to accessing pulmonary rehabilitation. In a questionnaire sent to healthcare professionals, primarily doctors and nurses, 84.7% perceived that rehabilitation was beneficial to their patients with lung cancer.<sup>50</sup> However, only 59.3% of health care professionals (primarily nurses and doctors) reported that they would initiate a referral to rehabilitation services.<sup>50</sup> Barriers to referral were: lack of knowledge about services, long-wait list times, and the perceived idea patients did not want rehabilitation services. Another study found similar results. The major barriers to access were lack of knowledge about palliative care/rehabilitation services and lack of physician referral.<sup>47</sup> Patients diagnosed with lung cancer were half as likely to access pal-

liative care/rehabilitation services when compared to patients diagnosed with another cancer type.<sup>47</sup> Due to the high-level of symptom burden experienced by patients with lung cancer, this information warrants further investigation. Although, the survival rate for lung cancer is shorter as compared to other cancers, palliative care and rehabilitation should nevertheless be started in these patients as early as possible to assist with symptoms and QoL issues.

#### End-of-Life care

In the advanced stages of cancer, addressing unresolved psychological issues may improve physical well-being and assist in managing other symptoms. A case-report describes a woman with advanced lung cancer who presented to an emergency department with worsening dyspnea.<sup>38</sup> She was referred to an acute palliative care unit. While there, it was discovered that she was supposed to be married the weekend she was admitted to hospital. In consultation with the patient and her family, it was determined that the wedding should take place in the patient's hospital room. After the wedding the patient's dyspnea, anxiety, depression, and well-being scores all improved.<sup>38</sup> This highlights the important impact taking the patient's whole self into context and treating all aspects of the patient's suffering can help in symptom management and alleviate physical as well as psychological suffering.

In the last week before death, self-reported dyspnea greatly increased in patients with cancer, intensifying as death approached, whereas depression decreased.<sup>43</sup> Pain and nausea were reasonably well controlled. Although, dyspnea may be unavoidable in the last stages of life, studies aimed at discovering novel interventions to assist in managing this distressing symptom at end-of-life are warranted.

Interestingly, patients with lung cancer at end-of-life in a palliative care unit experienced less dyspnea as compared to the same patient population cared for at home.<sup>48</sup> Therefore, some interventions are effective at decreasing dyspnea right before death. However, there is still much that can be learned about how to manage dyspnea in the actively dying.

#### Interstitial Lung Disease

Interstitial lung disease is an umbrella term for over 200 different types of diseases that primarily affect the parenchyma of the lungs. Interstitial lung disease can be broadly separated into known causes (medications, autoimmune conditions, environmental exposure) or unknown causes (idiopathic pulmonary fibrosis). They are a progressive, debilitating group of diseases and once diagnosed the median survival time is 2-3 years.<sup>58</sup> Aside from lung transplantation there are no viable treatment options available that impact mortality rates.<sup>54</sup> Patients with interstitial lung disease experience shortness of breath, cough, and insomnia. Shortness of breath is a common symptom among persons

nearing end-of-life, with over 90% of patients with interstitial lung disease experiencing it.<sup>52,55</sup> Patients expressed frustration at the way their illness limits their abilities to carry out activities of daily living and how it impacts their independence. The goals of managing interstitial lung disease should therefore involve maintaining function, improving QoL, and reducing disease related complications. There is strong evidence that pulmonary rehabilitation can improve 6 minute walk test outcomes (increasing patient endurance), moderate evidence that it can improve QoL, and it may assist with managing dyspnea for patients with fibrotic interstitial lung disease despite decreases in lung function.<sup>51,54-56</sup> However, there are no guidelines for maintenance of pulmonary rehabilitation for these patients once the program finishes. The benefits of pulmonary rehabilitation for patients with interstitial lung disease are not as sustained as compared to patients with COPD after the program has ended.<sup>54,55,58</sup> This could be due to a non-tailored pulmonary rehabilitation protocol given to patients with interstitial lung disease or the lack of a formal maintenance program.

Most patients with interstitial lung disease (particularly idiopathic pulmonary fibrosis) understand they have a progressive and eventually terminal diagnosis however, many do not understand their prognosis or how the disease will manifest in the later stages.<sup>57</sup> A study showed that only 13.7% of patients with interstitial lung disease were referred to palliative care.<sup>55</sup> Palliative care has a central role for caring for and educating patients with interstitial lung disease and patients should be referred to these services at the time of diagnosis. Poor communication and coordination of care may occur<sup>53</sup> therefore, organization of care and improved communication across disciplines, including with the patient themselves regarding disease progression, is needed. In an attempt to improve communication, a trial called Hospital2Home was tested.<sup>53</sup> The trial involved the patient, their carer, a Hospital2Home nurse, a general practitioner, a community nurse, a respiratory nurse, and a community palliative care nurse (as well as any other health/social care professional involved in the patient's care they felt were important to attend). Before the case conference, the Hospital2Home nurse contacted the patient to discuss which issues were of importance to them and what they hoped to achieve from the case conference. During the case conference, current and anticipated issues were discussed including physical, psychological, social, and spiritual concerns. If appropriate, end-of-life issues were also discussed. At the end of the meeting an action plan was agreed upon for each concern discussed and assigned to a healthcare professional.

Afterwards an individualized care plan was drafted. This plan was then communicated to all healthcare professionals involved in delivering care to that patient. Overall, this resulted in improvement of symptom control and QoL, including anxiety and depression, for patients receiving the intervention.<sup>53</sup> Therefore, involving all members who provide patient care, whether they be a family physician, palliative care nurse, or respiratory therapist leads to overall satisfaction and improved health outcomes in the patient.

Pulmonary rehabilitation programs are usually designed around patients living with COPD and may or may not be generalizable to persons with interstitial lung disease. The needs of patients with interstitial lung disease, including different physiological reasons for exercise limitations, quicker disease progression, and shorter survival times, contrast the trajectory experienced by patients with COPD who may live longer and progress more slowly across their disease course.<sup>54,57</sup> Although, patients with interstitial lung disease appreciated the general information given in pulmonary rehabilitation related to COPD, they preferred information more tailored to their condition including how to manage cough and strategies to limit disease progression.<sup>57</sup> The majority of patients interviewed for a study voiced the opinion that they would like to discuss end-of-life issues in pulmonary rehabilitation, once again suggesting this may be an appropriate setting to begin this conversation.<sup>57</sup> Many patients also supported the group nature of discussing end-of-life issues and actually preferred it to individual meetings.

Pulmonary rehabilitation should therefore strive to address and tailor programs to the differing disease populations it targets and serves.

#### Huntington's disease

Huntington's disease is a terminal genetic condition which mainly results in death from complications due to poor pulmonary function.<sup>59</sup> One study in the current review reported the effects of a respiratory muscle training program piloted on randomized patients with Huntington's disease. The trial consisted of home-based inspiratory (5 sets of 5 repetitions) and expiratory (5 sets of 5 repetitions) muscle training, 6 times a week for 4 months. At the end of the trial, lung function improved, but there were smaller non-significant effects on dyspnea and the 6-minute walk test.<sup>59</sup> Although, Huntington's disease may not be as prevalent as COPD or cancer, patients still experience progressive decline and eventual death due to failed pulmonary function. Further studies are needed to investigate whether or not pulmonary rehabilitation and palliative care provide benefit in this patient population and since the disease can be detected very early on through genetic testing, the appropriate time to initiate these interventions.

#### DISCUSSION AND CONCLUSION

Although, pulmonary rehabilitation and palliative care were addressed above in individual sections and it was suggested to tailor therapy to disease, there were also studies that looked at combining rehabilitation across different diseases. One study looked at a group exercise intervention including patients with cancer, advanced respiratory diseases, and amyotrophic lateral sclerosis (ALS) and found beneficial effects of the exercise class across all patient groups.<sup>33</sup> Patients reported improvements in physical function, a positive effect on the ability to complete activities of daily living, as well as enhanced mood. The environment was also described as supportive, allowed sharing of



information, and promoted self-management. It was not the social interactions alone however, that provided the benefit as one study showed that patients with COPD randomized to an exercise group *versus* a social group (unrelated to exercise) only the exercise group showed improvements in the number of steps taken.<sup>35</sup> The group delivery of a pulmonary rehabilitation program across different disease states still provided benefits, while it also allowed for an economical cost-benefit ratio. Hospices or palliative care units could therefore provide a pulmonary rehabilitation program for all of their patients regardless of the type of disease they have.

While there are a number of trials examining the benefits of pulmonary rehabilitation in patients with COPD, there is a corresponding lack of trials examining pulmonary rehabilitation in other diseases such as lung cancer, interstitial lung disease, and Huntington's. Most pulmonary rehabilitation programs are based around COPD and its disease specific requirements. It would be of value if tailored pulmonary rehabilitation programs were offered to other patient groups and the outcome of these programs were monitored.

A common theme emerging across patients with COPD, cancer, and/or interstitial lung disease is the lack of knowledge regarding palliative care and pulmonary rehabilitation and the benefits both services can provide. Patients are frequently not being referred to these services<sup>12,21,26,47,50,55</sup> and even if they are, there are considerable barriers that must be overcome in order for the patients to be able to attend pulmonary rehabilitation. Healthcare providers need to be educated about pulmonary rehabilitation and the evidence that supports its benefits in patients with a wide degree of chronic as well as malignant conditions. Barriers to access need to be overcome. There is promise in pulmonary rehabilitation programs being offered remotely by telerehabilitation. Further studies, should examine if patients received as much benefit from shorter telerehabilitation programs as they do from traditional hospital based 12-week programs.

Pulmonary rehabilitation has repeatedly been shown to be beneficial in helping to manage dyspnea, anxiety and depression, and functional capabilities of patients suffering from chronic lung diseases. Although, much evidence exists regarding its benefits, patients are frequently not referred soon enough or not referred at all to pulmonary rehabilitation and palliative care services. Patients and healthcare providers should be educated on the benefits of both services. An important concept is one of adaptability. Although, chronic lung diseases present with similar symptoms, including dyspnea, tailored and individualized plans appear to be important to the success of these programs. Pulmonary rehabilitation has been shown to be beneficial in even advanced stages of disease, so it is an appropriate intervention to give in a palliative care setting. The end goal of palliative care and pulmonary rehabilitation is to ensure the physical and emotional well-being of the patient and to enable function while managing symptoms. Pulmonary rehabilitation and pallia-

tive care should therefore synergistically work together to provide patients with the best possible outcome with the time they have left.

#### COMPETING INTEREST

The authors declare that they have no competing interest.

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