

Psychological Aspects of Pulmonary Rehabilitation in Chronic Obstructive Pulmonary Disease

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Abstract

As a leading cause of disability that often leads to death, chronic obstructive pulmonary disease (COPD) can be characterized as both a chronic illness and a life-threatening one. As a result, the experience of individuals with COPD can include psychological concerns that are associated with both rehabilitation and palliative care. At the same time, the often-uncertain trajectory of COPD obscures a clear transition from rehabilitation to palliative care. It is not surprising, therefore, that treatments aimed at addressing patients' rehabilitative and palliative needs largely proceed independently of each other.

This dissertation contains two studies conducted with patients participating in a pulmonary rehabilitation program for COPD ($N = 242$). Separately, each study stems from a research tradition grounded in either the rehabilitative or palliative approach to treatment. Together, the studies highlight an opportunity for a model of more integrated care. Study 1 is derived from the rehabilitation literature and focuses on the issue of "catastrophizing" about breathlessness. Catastrophizing is characterized by a magnification of a symptom's threat value, rumination about its perceived negative impact, and a sense of helplessness in addressing it. In some medical conditions with a primary symptom, such as chronic pain, catastrophizing demonstrates a strong relationship with the development of disability. Study 1 examines whether this relationship is found in the context of breathlessness. The study also reports the initial validation of the Breathlessness Catastrophizing Scale (BCS) as a means of assessing this phenomenon.

Study 2 has its conceptual basis in the palliative care literature and highlights patients' existential concerns around loss of dignity. Loss of dignity is a central construct in recent health care debates, because it is a primary reason underlying the requests of terminally ill individuals

to seek medically hastened deaths (i.e., euthanasia or assisted suicide). Until now, however, loss of dignity has only been examined among patients with cancer. Study 2 examines whether loss of dignity is as prevalent among those with advanced COPD, and whether it improves with treatment.

In Study 1 the BCS was found to be a reliable measure of breathlessness catastrophizing, with good convergent validity and sensitivity to change. Interestingly, it appears that breathlessness catastrophizing need not be a barrier to functional improvement in COPD. In Study 2, a “fractured” sense of dignity was found among 13% of patients with advanced COPD, suggesting that it is at least as prevalent as among those receiving palliative cancer care. It was also evident that loss of dignity is amenable to change with appropriate rehabilitation. This finding is important for societal debates regarding the provision of medically hastened deaths, which are often described as offering “death with dignity”. Together these studies demonstrate that in an interdisciplinary environment, such as the pulmonary rehabilitation program, not only is collaboration possible, but the distinct rehabilitative and palliative needs of patients can be met.

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Saying this has been an adventure would be a severe understatement. It has been exciting and arduous; inspiring and humbling. As with any great journey it is the company of those with whom you share it that makes every difference. Since there are hardly words adequate, I offer my gratitude simply.

G-d, my *sine qua non*.

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To those not with us today who are with us today

To those living and passed

And those in the midst of both

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Statement of Contributions

The research reported in the dissertation represents the culmination of an evolutionary process. In the clinical programs of The Ottawa Hospital, there has been an interest in identifying common themes that may have broad applicability to a range of medical conditions. This underlying interest is reflected in the issues addressed in the dissertation. Although the issues may have arisen in one area of psychological research, it was possible that they would have relevance in other areas as well, and specifically in the context of chronic obstructive pulmonary disease (COPD). Thus, from the chronic pain literature comes the interest in “catastrophizing”, and the question of whether there might be a fear-avoidance component to disability in COPD. From the palliative care literature comes the emphasis on the preservation of dignity.

Curiosity around these themes led to the inclusion of relevant questionnaires and interview measures being integrated into clinical assessments in the pulmonary rehabilitation program at The Rehabilitation Centre. When reviewing graduate school research options, Brahm Solomon and Dr. Keith Wilson mapped out the original plan to draw on these data for a series of studies that would identify the prevalence, correlates, and sensitivity to change of breathlessness catastrophizing and loss of dignity.

Patients in the pulmonary rehabilitation program (PRP) are well documented from medical, functional, and psychological perspectives. Although there are inherent limitations in chart reviews, the quality and completeness of the data are generally good on this service. Since both dissertation studies are rather unique “proof-of-concept” studies in the COPD literature, the chart review approach was considered an appropriate way to launch this novel line of investigation.

Due to the fact that these studies followed a chart review design, this declaration serves to detail the role played by Brahm Solomon and the contributions made by others who were involved in the research, including Drs. Wilson (dissertation supervisor) and Peter Henderson, PRP clinicians, and manuscript co-authors.

Initial project conceptualization was developed in meetings including Brahm Solomon and Drs. Wilson and Henderson. As the psychologist directly involved in provision of services for PRP patients, Dr. Henderson offered essential insights into the nature of the PRP, the kind of data available, and guidance on how to assemble a collaborative team of clinician-researchers. Following these meetings, the dissertation's theoretical overview was developed by Brahm Solomon and Dr. Wilson. The research protocol was developed by Brahm Solomon and Drs. Wilson and Patricia Poulin, with input from co-investigators Drs. Henderson, John Kowal, and Douglas McKim, and was approved by the Ottawa Hospital Research Ethics Board (now known as the Ottawa Health Science Network Research Ethics Board) and the University of Ottawa Office of Research Ethics and Integrity. The dissertation proposal was prepared by Brahm Solomon, under the supervision of Dr. Wilson, with additional input and final approval provided by internal dissertation committee members Drs. Tim Aubry, Kim Corace, and Sophie Lebel.

Though raw data collection was conducted by PRP clinicians for the purpose of clinical care, Brahm Solomon performed all chart reviews, database construction, data management, and analyses. Interpretation was primarily handled by Brahm Solomon and Dr. Wilson, with some guidance around pulmonary measures by charge respiratory therapist Carole LeBlanc, and physiotherapy measures by physiotherapists Nancy Kukulka and Lyne Lavallée.

Both article manuscripts were prepared with the same team of co-authors, including Brahm Solomon, Drs. Wilson, Henderson, Poulin, Kowal, and McKim. As first author, Brahm

Solomon was the primary author of both manuscripts. Dr. Wilson provided theoretical and methodological input and editing during each phase of preparation. Drs. Henderson, Poulin, Kowal, and McKim provided notes on the manuscript drafts and revisions, according to their areas of expertise. All co-authors gave final approval for the manuscripts as submitted. The first article, “A Breathlessness Catastrophizing Scale for chronic obstructive pulmonary disease,” has been published in *Journal of Psychosomatic Research*. The second article’s manuscript, “Loss of Dignity in Severe Chronic Obstructive Pulmonary Disease,” is currently under review at *Journal of Pain and Symptom Management*. This study was also presented as a poster at the 76th Annual Convention of the Canadian Psychological Association, where it received a Student Research Award for Excellence in Health Psychology Research.

This dissertation has been prepared by Brahm Solomon under the supervision of Dr. Wilson, with additional input from internal dissertation committee members Drs. Aubry, Corace, and Lebel.

Chapter 1

- Introduction -

Introduction

As of 2010, chronic obstructive pulmonary disease (COPD) was identified as the sixth leading cause of years lived with disability in the U.S. and the fourth leading cause of death (US Burden of Disease Collaborators, 2013). As such, COPD cannot be categorized easily as only a chronic illness or a terminal one. With dyspnea as a central feature causing substantial disability, efforts are reasonably focused on rehabilitation. Nevertheless, despite ongoing pharmacological and surgical developments, the prognosis for advanced COPD ultimately includes deterioration and eventual death. Therefore, for many individuals, palliative care becomes a necessity. Whereas other terminal illnesses allow for the differentiation of, and even transition from, rehabilitation to palliative care, the often-unclear trajectory of COPD does not.

Psychological research can contribute to both aspects of COPD treatment: rehabilitation and palliative care. This dissertation comprises two studies that highlight these two perspectives on COPD. They are based in an interdisciplinary pulmonary rehabilitation program, in which a cohort of patients was assessed before and after treatment (see Appendix A for further details about the program).

Study 1 investigates an issue that is a frequent research topic in rehabilitation, where it has been studied most extensively in patients with chronic pain. The issue involves the relevance for rehabilitation of “catastrophizing” about symptoms. The specific question can be framed as, “To what extent do patients with COPD catastrophize about dyspnea, their most pervasive symptom?” This question is addressed with a psychometric study to develop a measure of breathlessness catastrophizing.

Study 2 is derived from palliative care, where the concept of “death with dignity” has become both a focus of research and a rallying cry for social action. COPD patients in

rehabilitation have an illness that may ultimately be fatal, but not necessarily in the imminent future. The research question underlying Study 2, therefore, is, “Is loss of dignity a relevant consideration among patients with advanced COPD who are undergoing rehabilitation?” The study reports the prevalence and correlates of clinically significant loss of dignity, and its response to rehabilitation treatment.

Clinically, rehabilitation and palliative care sometimes proceed as “two solitudes,” even with the same patients. The overarching theme of the dissertation is to encourage greater understanding, integration, and collaboration between these two important disciplines.

Pathophysiology of COPD

COPD is a progressive degenerative lung disease. It is caused primarily by first-hand smoke, although second-hand smoke and other environmental pollutants can also contribute (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2013). Symptoms are similar to those of asthma, bronchitis, and emphysema combined. Disease of the small airways leads to contracting spasms as well as inflammation of the tissue, restricting expiratory airflow. Lung tissue damage diminishes elastic recoil, reducing carbon-dioxide expulsion during exhalation and thereby oxygen intake during inhalation. Together these problems severely limit airflow and cause dynamic hyperinflation, resulting in pronounced dyspnea, coughing, and sputum production.

Risk Factors

Risk factors for COPD include genetics, history of respiratory infection, and aging (GOLD, 2013). The primary genetic risk factor identified thus far is alpha-1 antitrypsin deficiency (A1AD) (Stoller & Aboussouan, 2005). Alpha-1 antitrypsin inhibits elastase, an enzyme that helps maintain the functioning of connective tissues. When insufficiently controlled due to

A1AD, elastase destroys elastic fibers, resulting in emphysema. A history of respiratory infection has also been associated with diminished lung function (de Marco et al., 2011). The precise mechanism accounting for the association of age with the development of COPD is not clear, but it may involve some combination of predisposing biological characteristics and environmental exposure.

Diagnosis

According to the World Health Organization (WHO)-endorsed standards outlined by GOLD (2013), spirometric assessment of lung function is necessary in order to confirm a diagnosis of COPD. The spirometric measures required are the forced vital capacity (FVC) and forced expiratory volume in one second (FEV_1). The FVC is the volume of air that can be exhaled forcibly after full inspiration, measured in litres, while the FEV_1 is the volume of air that can be forcibly exhaled in one second, after full inspiration. Together these generate the fixed ratio (FEV_1/FVC). In healthy individuals this ratio is expected to be between 75 and 80%. For the purpose of confirming a diagnosis of COPD, a ratio of 70% or less is required (Zwar et al., 2011).

Prevalence

As of 2011, 4% of Canadians between the ages of 35-79 reported having a diagnosis of COPD. In contrast, 13% of Canadians were found to have a lung function score indicative of COPD when direct measurements were taken as part of the Canadian Health Measures Survey (CHMS) (Statistics Canada, Health Statistics Division [Statistics Canada], 2012). Buist et al. (2007) reported a prevalence of 10% among Canadians in an international survey examining national prevalence rates. The degree of underdiagnosis found by the CHMS is consistent with the estimates of 60 to 85% given by Decramer, Janssens, and Miravittles (2012). Overdiagnosis

also occurred, with 2% of those without measurable airflow obstruction reporting a diagnosis of COPD (Statistics Canada, 2012). Of those surveyed in the CHMS, 6% demonstrated airflow obstruction consistent with Stage I (mild) COPD and 7% with Stage II or higher (moderate to very severe).

Treatment

Since no cure currently exists, efforts to control COPD are divided between preventive measures, both educational and behavioural (e.g., smoking cessation), and treatments focused on alleviating symptoms.

Pharmacological and surgical approaches.

Among the chief symptoms, breathlessness or dyspnea is of particular concern when determining a patient's level of disability (GOLD, 2013). Physiological treatments for dyspnea consist of pharmacological and surgical approaches. Pharmacologically, bronchodilators and steroids are used to open the airways and reduce inflammation. Surgical options are far more limited, due to the systemic impact of the disease, and the risk of infection and complication. Where lung tissue is damaged to the point of minimal function, a bullectomy removes the tissue, eliminating a source of strain and energy drain on the respiratory system that can otherwise make better use of its reduced lung volume (GOLD, 2013).

Pulmonary rehabilitation.

For those with established COPD, the recommended treatment consists of pulmonary rehabilitation that addresses symptom and disability management (GOLD, 2013). Rehabilitation targets a number of problems that are not sufficiently addressed by medical interventions. These may include exercise de-conditioning, muscle wasting and weight loss, as well as psychological issues, such as anxiety and depression, and social concerns such as isolation and limited

participation in activities. Key components to a pulmonary rehabilitation program are exercise training, smoking cessation, nutrition counseling, education, and psychological interventions (see Appendix A for further details about the program).

A growing number of studies are demonstrating support for the efficacy of pulmonary rehabilitation. Functionally, exercise performance and muscle strength improve significantly (Lacasse et al., 2002; Puente-Maestu, SantaCruz, Vargas, Martinez-Abad, & Whipp, 2003; Rubí et al., 2010; van Ranst, Otten, Meijer, & van t' Hul, 2011), as do walking distance, dyspnea and fatigue (Gigliotti et al., 2003; Román et al., 2013; Rubí et al., 2010). The number of exacerbations, hospitalizations, and days of hospitalization decline (Rubí et al., 2010), patients' sense of mastery and quality of life increase (Goldstein, Gort, Stubbing, Avendano, & Guyatt, 1994; Lacasse et al., 2002; Román et al., 2013), and there are significant reductions in symptoms of depression and anxiety (Kozora, Tran, & Make, 2002; Román et al., 2013; Tselebis et al., 2013).

The Role of Psychological Factors

Although spirometry is used as a key measure of lung function, beyond a certain degree of impairment, it is often a poor predictor of a patient's level of disability (Bednarek, Maciejewski, Wozniak, Kuca, & Zielinski, 2008; Eisner et al., 2010). Therefore, other contributing factors, including psychological concerns, have often been related to functional outcomes (Laurin, Moullec, Bacon, & Lavoie, 2012) and exacerbations (Laurin et al., 2009) in this population.

Depression.

Approximately 25% of individuals with COPD report clinically significant depressive symptomatology (Zhang, Ho, Cheung, Fu, & Mak, 2011). Among those, 61-71% meet criteria

for a major depressive disorder, 10% for a minor depressive disorder, and 19-38% for dysthymia (Kunik et al., 2005; Laurin et al., 2007).

In this population, depression has been associated with lower health status (Gudmundsson et al., 2005), poorer exercise performance (Giardino et al., 2010), decreased mobility, functional impairment, and more global disability (Ng, Niti, Fones, Yap, & Tan, 2009). Depressed COPD patients also rate health-related quality of life (Giardino et al., 2010) and overall quality of life (Ng et al., 2009) as poorer. Depression has been found to impair self-management of COPD (Yohannes, Hann, & Sibbald, 2011) and is associated with a higher risk of exacerbations and a higher frequency of exacerbations (Quint, Baghai-Ravary, Donaldson, & Wedzicha, 2008). When exacerbations do occur, they are more likely to result in hospitalizations (Xu et al., 2008), hospitalizations are likely to last longer (Ng et al., 2007), and there is an increased risk of readmission or death in the following weeks (Abrams, Vaughan-Sarrazin, & Vander Weg, 2011). As a result, Canadian Thoracic Society guidelines emphasize the importance of the treatment of depression in order to reduce the frequency and severity of exacerbations (O'Donnell et al., 2007).

Anxiety.

Anxiety disorders are also common among individuals with COPD, affecting 10-55% of patients (Willgoss & Yohannes, 2013). Prevalence estimates for specific disorders include: generalized anxiety disorder (39%), panic disorder (12-43%), anxiety disorder not otherwise specified (24%), and posttraumatic stress disorder (2-15%) (Kunik et al., 2005; Laurin et al., 2007).

As with depression, anxiety is associated with lower health status (Eisner et al., 2010; Gudmundsson et al., 2005; Xu et al., 2008). Anxiety has been found to have a negative impact on

exercise performance and functional limitations (Eisner et al., 2010; Giardino et al., 2010), including shorter walk distances, diminished maximum workload on cardiopulmonary exercise testing, and greater dyspnea (Giardino et al., 2010). It is associated with self-reported disability and worse global and disease-specific health-related quality of life (Eisner et al., 2010; Giardino et al., 2010). Anxiety has been associated with length of exacerbations (Xu et al., 2008) and has been found to increase risk of exacerbations requiring hospital-based care (Eisner et al., 2010). It has been associated with more frequent hospitalization (Eisner et al., 2010; Gudmundsson et al., 2005; Xu et al., 2008; Yohannes, Baldwin, & Connolly, 2005) and increased risks of hospital readmission (Abrams et al., 2011; Gudmundsson et al., 2005), or death within the following weeks (Abrams et al., 2011). Eisner et al. (2010) suggest that treatment of anxiety may improve outcomes even after medical treatments aimed at reducing COPD severity have been maximized.

Recently, research has begun to expand beyond broad psychopathological constructs such as depression and anxiety into particular affective and cognitive processes that may influence how one attends and responds specifically to the symptom of dyspnea. Foremost among these are anxiety sensitivity and catastrophizing.

Anxiety sensitivity.

Anxiety sensitivity is the fear of physiological symptoms of anxiety due to the belief that they are harmful. Studies suggest that anxiety sensitivity promotes hypervigilance to bodily sensations and fearful interpretations of symptoms when they occur (Austin & Kiropoulos, 2008; Cox, 1996). Among patients with COPD, anxiety sensitivity has been found to predict greater dyspnea-related activity avoidance, even after controlling for diagnosed anxiety disorders and degree of pulmonary dysfunction (Simon et al., 2006).

Catastrophizing.

Catastrophic thinking or interpretation has been related to the construct of anxiety sensitivity in the COPD literature, and is regarded as a byproduct of hypervigilance to bodily sensations (Livermore, Sharpe, & McKenzie, 2007, 2012). Catastrophic interpretations can lead to anxiety and panic symptoms as well as to anxiety disorders, and more generally result in heightened physiological arousal and dyspnea (Livermore et al., 2012). Although catastrophic thinking can be framed as a situational response, with anxiety sensitivity as the predisposing trait, it is also believed that “catastrophizing” can develop in its own right (Drahovzal, Stewart, & Sullivan, 2006).

Catastrophizing is an exaggerated negative cognitive orientation toward noxious stimuli and experiences, characterized by rumination about those experiences, magnification of their threat value, and perceived inability to control them (Chaves & Brown, 1987; Sullivan, Bishop, & Pivik, 1995). Catastrophizing has been associated with the development of disability in other chronic medical conditions that are characterized by a predominant symptom, particularly chronic pain. In some studies of individuals with chronic pain, catastrophizing has been found to have a stronger correlation with disability than the pain itself (Crombez, Vlaeyen, Heuts, & Lysens, 1999; Helsen, Goubert, Peters, & Vlaeyen, 2011). In fact, this has led to the development of a fear-avoidance model of disability in chronic pain. This model proposes that the way in which a symptom is interpreted will influence the individual’s level of functioning. If the symptom is appraised as threatening, then the individual may respond with fear, hypervigilance to its presence, and avoidance of activity that may trigger it. In the long term these responses are counterproductive for rehabilitative efforts and can lead to further disability (Vlaeyen & Linton, 2000). In the case of COPD, it would be predicted that patients who

catastrophize about dyspnea would similarly become fearful of or hypervigilant to the experience of breathlessness, perhaps leading to an avoidance of activities that might trigger shortness of breath (Boot, Heijmans, van der Gulden, & Rijken, 2008; Boot, van Exel, & van der Gulden, 2009; Simon et al., 2006; Sutton, Cooper, Pimm, & Wallace, 1999).

Rehabilitation interventions focused on improving the affective component of dyspnea can improve functioning and limit disability without changing underlying disease pathology (Cooper, 2009; Scherer & Schmieder, 1997). Hence, it has been suggested that psychological factors may play a role in explaining why different individuals with the same degree of objective pulmonary impairment vary with respect to disability in daily activities (Omachi et al., 2010). Presumably, catastrophizing individuals with high anxiety sensitivity engage in physical therapy at suboptimal levels and exhibit a more general unwillingness to engage in programs that are heavily focused on exercise (Janssens et al., 2011). The starting point for these patient responses, according to a cognitive-behavioural model, is the catastrophic over-interpretation of dyspneic symptoms (Livermore et al., 2012).

The IBPQ and the need for a new measure of catastrophizing.

At present the sole catastrophizing measure available for use with individuals with COPD is the Interpretation of Breathing Problems Questionnaire (IBPQ; Sutton et al., 1999). Fourteen scenarios are presented to respondents (e.g., “You are in a smokey pub and your chest begins to feel tight.”) and they are asked to respond briefly to qualitative questions, as well as provide ratings of anxiety, likelihood of becoming ill, and likelihood of dying in each scenario. Scores on each of the rating items have been correlated with the HADS anxiety score, with correlations ranging from .22 to .64. Importantly, however, there is no evidence that IBPQ scores are related to measures of functional performance. Moreover, its format may be difficult for some patients

to complete and includes scenarios that may not be relevant to all individuals. A shortened eight-scenario form (IBPQ-S; Gurney-Smith, Cooper & Wallace, 2002) demonstrated a moderate correlation ($r = .34, p < .04$) between the IBPQ-S and HADS anxiety scores. However, when the individual scenarios were correlated with the HADS anxiety score, several failed to correlate significantly.

In contrast, the Breathlessness Catastrophizing Scale (BCS) is being introduced here as an alternative measure offering several advantages. (1) The BCS items directly reflect experiential aspects of catastrophizing (e.g., “There’s nothing I can do to reduce the intensity of the breathlessness”); (2) qualification as catastrophic thinking is not limited to an increase in anxiety, illness or death; (3) the BCS is concise, with each item requiring a single quantitative rating, with no narrative response requirement or qualitative interpretation; (4) the BCS is a modification of the well-established Pain Catastrophizing Scale (PCS; Sullivan et al., 1995), which represents the standard in the assessment of catastrophizing among patients with chronic pain. Hence, it may permit more direct inferences to be drawn between studies of catastrophizing in COPD with those of chronic pain.

The initial validation of the BCS is presented in the manuscript of Study 1.

Palliative Care

In contrast to approaches that focus on the treatment of disease and associated symptoms, or on the rehabilitation of functional performance, palliative care aims to improve the quality of life of patients and their families when facing life-threatening illness. Its focus is on the prevention and relief of suffering, whether physical, psychosocial, or spiritual. Unlike most non-palliative approaches, palliative care seeks neither to postpone nor hasten death, and actively engages in considerations of dying as a normal process. It addresses both the needs of the patient

and his or her family, providing care during the illness and when bereavement begins (WHO, 2002).

Palliative care and COPD.

COPD is not curable and symptoms are generally irreversible. Although prognoses are rarely clear, a “typical” course of COPD would include a progressive decline in functioning. Long-term symptoms, such as dyspnea, are prominent features of the disease, as are acute exacerbations. The necessity for the involvement of palliative care may be indicated by the persistent presence of severe symptomatology despite optimally tolerated treatment. It may also be indicated by dyspnea that limits daily activities at rest or with minimal exertion. However, the necessity for palliative care is ultimately indicated when a patient identifies a need, and not based solely on clinical diagnoses or disease stage (Bausewein et al., 2010).

Although there is evidence that those with severe COPD could benefit from palliative care (Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009; Elkington, White, Addington-Hall, Higgs, & Pettinari, 2004; Habraken, Willems, de Kort, & Bindels, 2007), frameworks for its implementation are not well-explored. Therefore, the question remains as to which approaches are best suited for this population (Gysels & Higginson, 2010). As palliative care models for those with cancer are better established, some have suggested that they represent a reasonable starting point for considerations of palliative care in COPD. Where this has been done, studies have found that patients with COPD demonstrated a symptom profile that overlaps with that of lung cancer. Breathlessness was a common primary symptom, followed by drowsiness, lack of energy, and cough (Bausewein et al., 2010).

Although palliative care is a recognized need of some individuals with COPD (GOLD, 2013) no formal guidelines for the provision of such care have been established by GOLD or any

other recognized health policy organization. National Health Service Scotland, however, provides the following guidelines for palliative care in advanced lung disease (National Health Service Scotland, 2010).

Care begins with an initial assessment that involves: (1) verification that current treatment is implemented optimally; (2) continuance of current treatment where possible, with the additional engagement of palliative support services and broader social support; (3) reduction or termination of treatment aimed primarily at underlying disease if treatment burdens outweigh benefits; and (4) review of patient and family understanding of the illness as well as its management and care options. The initial assessment is then followed by care planning, which involves: (1) the establishment of a mechanism for regular review or assessment; (2) an anticipatory care plan for future treatment, exacerbations and complications; (3) resuscitation orders; (4) the appointment of a welfare guardian, if future loss of decision-making capacities is of concern; (5) directives regarding life-supporting care; and (6) a plan of care for the last days of life. Clinicians may facilitate care planning, but where dedicated palliative care services are available, it is recommended that such services be sought. Due to the complex constellation of needs the patient may have, an interdisciplinary approach is considered essential for optimal care.

Contrasts with advanced cancer.

In contrast to patients with lung cancer, individuals with severe COPD have been found to have worse physical, social and emotional functioning, but receive less support from local or palliative nursing staff (Edmonds, Karlsen, Khan, & Addington-Hall, 2001; Gore, Brophy, & Greenstone, 2000). Although the prognosis of patients with COPD is less certain than those with cancer (Curtis, 2008), patients with Stage III and Stage IV COPD survive nearly five times as

long, on average. This suggests that palliative care needs are likely to arise earlier in the disease trajectory, and that patients must cope with their situation much longer (Bausewein et al., 2010).

Palliative care and existential concerns.

Palliative care can be distinguished from more traditional healthcare approaches in the attention it focuses on existential concerns. Although there is some variance in how such concerns are conceptualized, Yalom (1980) offers the broadest definition. According to Yalom, existential concerns focus on such themes as death, isolation, meaninglessness, and freedom. Kissane (2000) highlights the theme of death and discusses the experiences of meaninglessness and powerlessness in response to being confronted with the end of life. Kearney and Mount (2000) emphasize isolation from an internal source of meaning, hope, and purpose. In contrast, Murata (2003) and Millspaugh (2005) focus on isolation via the loss of relationships and autonomy, with Millspaugh also discussing the loss of self. Similarly, Cherny, Coyle and Foley (1994) see existential concerns as rooted in the self, through changes in identity and integrity. Finally, McGrath (2002) views these concerns as a byproduct of external interference in natural processes of connecting with life and creating meaning out of experience.

When existential concerns arise, they can manifest through physical and psychological symptoms (Kearney & Mount, 2000). Among those diagnosed with a terminal illness, existential concerns are significant correlates of their will to live (Chochinov et al., 2005). Although prominent existential crises are not universal among the terminally ill (Chochinov, Hack, Hassard et al., 2002; de Faye, Wilson, Chater, Viola, & Hall, 2006; Thompson et al., 2009; Wilson et al., 2009), when they do arise they can be so significant that even physical symptoms are considered secondary in comparison (Breitbart et al., 2000; Chochinov, Tataryn, Clinch, & Dudgeon, 1999).

Dignity.

Chief among existential concerns is the preservation of dignity. Dignity is defined as “the quality or state of being worthy, honored, or esteemed” (Merriam-Webster, 2003). In some ways it can be considered the guiding principle of palliative care. Even though approaches to care can differ significantly among patients with similar or disparate diagnoses, each could be considered to be safeguarding the dignity of the individual. It is in large part because of palliative care’s emphasis on dignity that it necessitates the inclusion of goals beyond symptom and disease management.

Although the manner in which any given individual will experience his or her sense of dignity is ultimately idiosyncratic, Chochinov, Hack, McClement, Kristjanson, and Harlos (2002) developed the Model of Dignity in the Terminally Ill to serve as a guide to the factors that are most likely to either enhance or diminish a person’s sense of dignity (see *Figure 1*). The model was developed on the basis of qualitative interviews with patients receiving palliative cancer care, who were asked to reflect on the experiences that impacted on their sense of dignity. Three broad dimensions were identified, with each comprising a number of sub-themes. The broad categories were considered to reflect Illness Related Concerns, Dignity Conserving Repertoire, and Social Dignity Inventory. Illness Related Concerns consist of medical and functional considerations, including level of independence (cognitive, functional) and symptom distress (physical, psychological). Dignity Conserving Repertoire consists of relevant attitudes and behaviours of the patient. These include Dignity Conserving Perspectives, such as sense of self, image projected, impact on others, and outlook, and Dignity Conserving Practices, such as present-focus, maintaining routine and seeking spiritual comfort. Social Dignity Inventory includes interpersonal issues such as privacy boundaries, social support, care tenor adopted by

clinicians, sense of burden to others, and aftermath concerns for bereaved loved ones. With recognition of the potential influence of these factors on the quality of life of patients with advanced illness, they can be taken into consideration in the broader context of care.

Dying with dignity.

In some respects, the concept of dignity at the end of life has become a focal point for divergent perspectives on the goals of palliative care. On the one hand, “dignity-conserving care” refers to care that conserves or repairs a dying patient’s physical, social, psychological, or spiritual integrity while he or she remains alive (Chochinov, 2002; Chochinov, 2007; Cook & Rocker, 2014). In line with the principles of palliative care, treatment seeks neither to hasten nor postpone death (WHO, 2002), instead viewing it as part of the context in which intervention occurs. Further, death is reframed as dying and is thereby conceptualized as a process (Chochinov, 2002; Chochinov, Hack, McClement et al., 2002; Gamlin, 1998; Proulx & Jacelon, 2004) or even a developmental stage (Byock, 1998). As such, interventions that fall under this approach may go beyond the treatment of symptoms and problems and encompass practices that promote personal growth.

However, the term “death with dignity” has also taken another meaning in recent health-care debates. For some, it now refers to the provision of medical means to end a patient’s life in order to alleviate suffering caused by a life-limiting condition (Loggers et al., 2013; Oregon Death with Dignity Act [ODDA], 1994). When such a condition is not amenable to treatment and offers little prospect of improvement, some jurisdictions allow for the option of hastening death, either by physician-assisted suicide or euthanasia. Where this option is available, loss of dignity is often cited as a primary reason for patients to request assistance in ending their lives (Ganzini, Goy, & Dobscha, 2009; Loggers et al., 2013; ODDA, 1994; van der Maas et al., 1991).

At present, such jurisdictions include: Belgium, Colombia, Luxembourg, the Netherlands, Switzerland, and several of the United States (i.e., Montana, Oregon, Vermont, Washington). The legislation that permits these practices is often framed as ensuring death with dignity by preserving the patient's autonomy in end-of-life decision-making, and showing compassion by limiting unnecessary suffering (ODDA, 1994; Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002). In fact, some jurisdictions have explicitly named this legislation, a "Death with Dignity Act" (ODDA, 1994; Washington death with dignity act, 2009).

Assessment of loss of dignity.

As with most palliative care research, studies examining dignity in the terminally ill have largely been conducted in patients with cancer. In these studies, it is the loss of dignity that has been the evaluative focus, which has been assessed using a clinician-administered interview item from the Structured Interview of Symptoms and Concerns (SISC; Wilson et al., 2004). With this assessment, a clinician-interviewer makes a number of inquiries about how well the patient is able to maintain "dignity and self-respect." The severity of concerns about loss of dignity are then rated on a 7-point scale ranging from 0 (*No Sense of Loss of Dignity*) to 6 (*Extreme*). Scores ≥ 3 correspond to the respondent having acknowledged that the loss of dignity is generally a significant problem.

Prevalence of loss of dignity.

Five studies have used the SISC loss of dignity item (LoDi) with individuals diagnosed with advanced cancer (Chochinov, Hack, Hassard et al., 2002; Chochinov et al., 2006; de Faye et al., 2006; Wilson et al., 2007; Wilson et al., 2004). As shown in Table 1, the majority (54-75%) of patients reported no loss of dignity. Another 15-40% reported a low level of loss, which was

not considered to represent a clinically significant concern. Only 5-10% of patients reported experiencing loss of dignity as a significant and ongoing problem, which Chochinov et al. have described as a “fractured” sense of dignity.

Correlates of loss of dignity.

Chochinov, Hack, Hassard and colleagues (2002) conducted a cross-sectional study in which they examined correlates of LoDi scores within a sample of 213 terminally ill patients with cancer. When compared with those who reported low to no loss of dignity, individuals with a fractured sense of dignity reported more difficulties with self-care, such as bowel functioning, toileting, bathing, and dressing, and were more likely to be receiving inpatient treatment. They were also more likely to report feeling depressed, hopeless, anxious, and to have lost the will to live. Their overall quality of life was significantly lower than those with an intact sense of dignity. Moreover, patients with a fractured sense of dignity were significantly younger, on average. In a subsequent regression analysis, concerns identified as unique and independent risk factors for the loss of dignity were the sense that one was being treated without respect or understanding and feeling like a burden to others (Chochinov et al., 2006).

At present, the issue of loss of dignity has only been examined among patients who have been receiving palliative care for cancer. Patients with severe COPD have many of the same medical and social support needs as people with cancer; indeed, their symptomatic and functional characteristics are often worse through much of the disease trajectory. Their prognosis is less predictable, however, which may explain why palliative care approaches for COPD are seldom considered until the very end of life.

It has yet to be determined whether the loss of dignity is a relevant concern for patients with COPD. In addition, there has never been a demonstration of whether a fractured sense of

dignity is amenable to change with appropriate intervention. These issues represent the main objectives of Study 2: (1) to identify the prevalence and correlates of loss of dignity among individuals with COPD, and (2) to examine whether the loss of dignity changes over time with participation in a pulmonary rehabilitation program.

Integrated Care

Although rehabilitation and palliative care often proceed independently as “two solitudes,” a model developed by Health and Welfare Canada (1987; see *Figure 2*, as adapted by the Canadian Hospice Palliative Care Association [CHPCA], 2002) proposes their integration into a single treatment plan. Here, rehabilitation and palliation are seen as complementary interventions instead of divergent, and are implemented concurrently instead of serially. This encourages palliative needs to be addressed anywhere in the disease trajectory (Bausewein et al., 2010; Higginson et al., 2014), and is in line with the demonstrated benefits of early integration of palliative care for symptom management and quality of life (Bakitas et al., 2009; Higginson et al., 2014; Higginson et al., 2009; Temel et al., 2010; Zimmerman et al., 2014).

At present, however, standard care fails to follow this model (Higginson et al., 2014; Rocker, Simpson, & Horton, 2015). For those with COPD this is especially problematic, as the symptom burden is higher than in those with comparable diagnoses, such as lung cancer (Joshi, Joshi, & Bartter, 2012). More severe breathlessness and distress throughout the course of the disease calls for a palliative approach often reserved for those at the end of life (Disler, Gallagher, & Davidson, 2012; Joshi et al., 2012; PAALiativ Project, 2014). At the same time, the often-unpredictable trajectory of the disease makes prognostication especially difficult (Murray, Boyd, & Sheikh, 2005), leaving the time for consultation or collaboration with palliative services all the more unclear (Pinnock et al., 2011). Overall, this results in poorer coordination of care

(Epiphaniou et al., 2014), and a lack of forward planning (Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005) for individuals for whom this is expressly recommended (Department of Health, 2011).

This disjointed approach effectively leaves individuals to engage in rehabilitation and palliation independently of each other. Consequently, intervention begins to follow two paths. The biomedical path focuses on neurophysiological mechanisms, pharmacological therapies, oxygen prescriptions and use of other gas mixtures, and exercise-based approaches (American Thoracic Society Committee on Dyspnea [ATS Committee], 2012). Here, the goals of rehabilitation are to restore lost function where possible and reduce or delay further decline (ATS Committee, 2012). Psychological interventions are often considered secondary, and palliative care is regarded as an additional service (Fromer, 2011). In contrast, the palliative path focuses on relieving the individuals' suffering when symptoms prove refractory to care. As such, emphasis is placed on identifying and addressing psychosocial and spiritual distress (WHO, 2002). Though each approach serves an important need of individuals with COPD, they rarely collaborate.

This dissertation will examine a pulmonary rehabilitation program as an example of how such collaboration could work. Though designed and focused around rehabilitative considerations, the program's interdisciplinary structure may also address some palliative concerns. Individually, the studies reported here will mirror the current state of care, with each following a path drawn from either the rehabilitation or palliative care literatures. Combined, their findings will offer a better understanding of how to foster greater service integration.

Summary

The two studies composing this dissertation address different aspects of the experience of individuals with COPD as they participate in a pulmonary rehabilitation program. One study is grounded in the rehabilitation literature, whereas the other is associated more closely with palliative care. Study 1 examines catastrophizing, a construct related to functional disability and rehabilitation in chronic pain. Dyspnea in COPD is a prominent primary symptom leading to disability, and in this sense it may be analogous to the experience of pain in chronic pain conditions. Study 2 examines loss of dignity in patients with severe COPD, who are at greatest risk for life-threatening exacerbations. Dignity is a central consideration in palliative care, and a fractured sense of dignity is associated with psychological, medical and functional outcomes in patients diagnosed with terminal cancer. Whether the loss of dignity is also relevant in COPD remains to be determined.

Together, these studies offer greater insight into what is often considered the “grey area” between rehabilitation and palliation, and the role that a pulmonary rehabilitation program can serve in this context. They help to bridge a gap between the rehabilitation and palliative care communities, bringing to each clinical audience a novel concept drawn from the literature of the other, to inform their multidimensional approach to the psychological care of patients with COPD.

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Table 1

Prevalence of Loss of Dignity Among Studies Using the Structured Interview for Symptoms and Concerns Dignity Item in Patients with Advanced Cancer

	Chochinov et al. (2002) ^a (N = 213)	Chochinov et al. (2006) (N = 211)	de Faye et al. (2006) (N = 52)	Wilson et al. (2004) (N = 69)	Wilson et al. (2007) (N = 381)	
Rating	%	%	%	%	%	Grouping
0 - None	54	95 ^b	75	60	75	Intact
1 - Minimal	30		4	20	10	
2 - Mild	9		11	12	8	
3 - Moderate	5	5 ^b	8	3	3	Fractured
4 - Strong	2		2	1	2	
5 - Severe	0		0	0	1	
6 - Extreme	0		0	4	1	

Note. Table entries are percentages of respondents who received interviewer ratings at each level or grouping of severity.

^aRefers to Chochinov, Hack, Hassard et al. (2002). ^bChochinov et al. (2006) only characterize patients as having an intact or fractured sense of dignity.

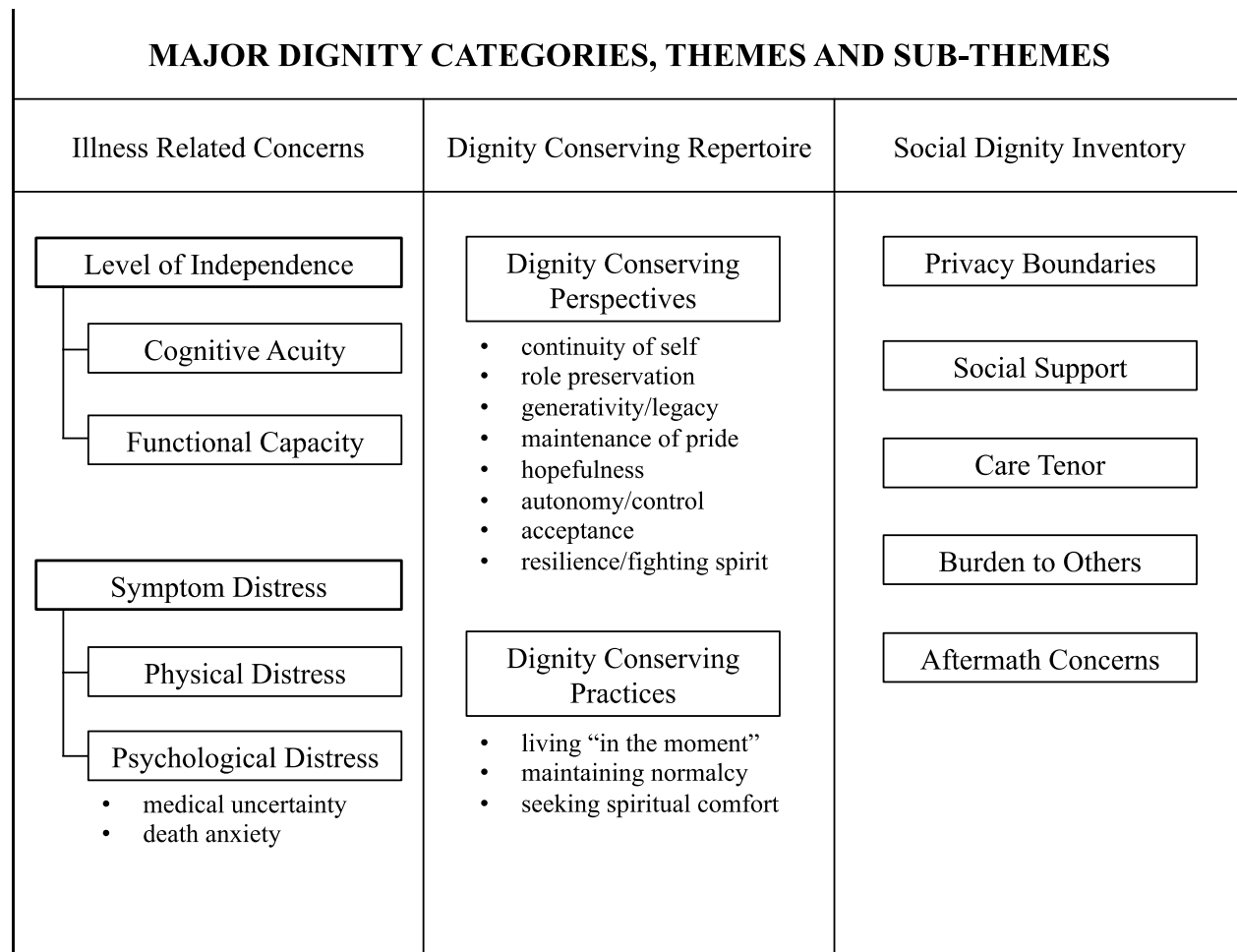
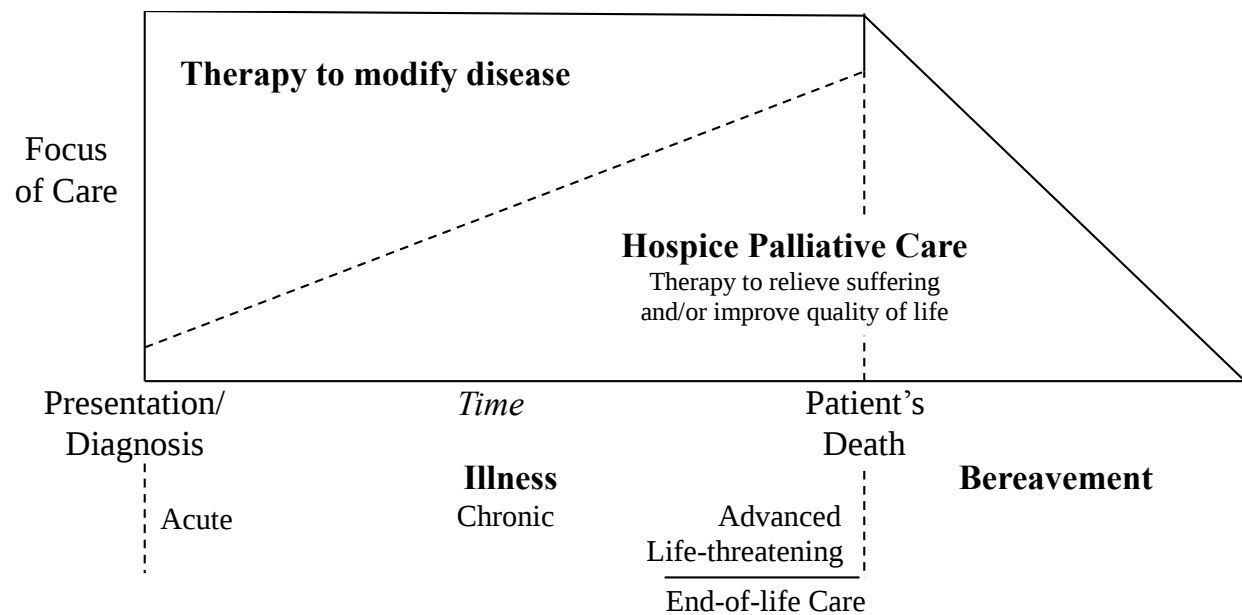


Figure 1. Model of Dignity in the Terminally Ill. Reproduced with permission of *Social Science & Medicine*. From Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: A developing empirical model. *Social Science & Medicine*, 54, 433-443. doi:10.1016/S0277-9536(01)00084-3



*Figure 2. The Role of Hospice Palliative Care During Illness. Reproduced with permission of the Canadian Hospice Palliative Care Association. From Canadian Hospice Palliative Care Association. (2002). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Ottawa, ON: Canadian Hospice Palliative Care Association; as adapted from Health and Welfare Canada, Federal Centre for AIDS, Expert Working Group on Integrated Palliative Care for Persons with AIDS. (1987, December). *Caring together* (29). Ottawa, ON: Health and Welfare Canada*

Chapter 2

- Study 1 -

“A Breathlessness Catastrophizing Scale for chronic obstructive pulmonary disease”

Solomon, B. K., Wilson, K. G., Henderson, P. R., Poulin, P. A., Kowal, J., & McKim, D. A.

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A Breathlessness Catastrophizing Scale for Chronic Obstructive Pulmonary Disease

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Abstract

Objective: Catastrophizing about breathlessness may be related to disability in patients with chronic obstructive pulmonary disease (COPD), but assessment options are limited. This study reports the initial validation of a 13-item Breathlessness Catastrophizing Scale (BCS).

Method: Pulmonary rehabilitation inpatients completed spirometric, functional performance and questionnaire assessments at admission ($N = 242$) and discharge ($n = 186$).

Results: The BCS comprised a unifactorial scale that demonstrated excellent internal consistency (Cronbach's $\alpha = .96$) and correlated with measures of anxiety sensitivity, depression, and self-efficacy, but not with performance on walk and stair-climbing tests. BCS scores improved robustly with rehabilitation, approaching a medium effect size ($d = .43$), and demonstrated a modest association with enhanced performance in a stair-climbing test of exercise tolerance.

Conclusion: The BCS is a reliable measure of catastrophizing in severe COPD that has good convergent validity and sensitivity to change. Its association with functional performance requires further investigation. However, it appears that a high level of catastrophizing about breathlessness is not a barrier to functional improvement with inpatient pulmonary rehabilitation.

Keywords: catastrophizing, chronic obstructive pulmonary disease, disability, rehabilitation, depression, anxiety

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive degenerative lung disease that causes cough, sputum production, and disabling breathlessness (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2013). As of 2010, COPD was identified as the fourth leading cause of death in the U.S. and the sixth leading cause of years lived with disability (US Burden of Disease Collaborators, 2013). For those COPD patients who are limited functionally by dyspnea, the recommended treatment includes pulmonary rehabilitation to improve symptom management and participation in activities of daily living (GOLD, 2013).

According to the WHO-endorsed standards outlined by GOLD (2013), spirometric assessment of lung function is required to confirm a diagnosis of COPD. Spirometry, however, is often a poor predictor of a patient's level of disability (Eisner et al., 2010). In contrast, psychological factors have often been related to functional outcomes in this population (Laurin, Moullec, Bacon, & Lavoie, 2012). Depressive symptoms, for example, have been associated with decreased mobility and functional status (Cao, Ong, Eng, Tan, & Ng; Gudmundsson et al., 2005; McCathie, Spence, & Tate, 2002; Ng, Niti, Fones, Yap, & Tan, 2009; Ng et al., 2007; Norwood, 2006), as well as more frequent and longer hospital admissions (Ng et al., 2007). Similarly, anxiety has been related to decreased physical health, exercise performance (Eisner et al., 2010), functional performance status (Eisner et al., 2010; Giardino, Curtis, Abelson et al., 2010; Giardino, Curtis, Andrei et al., 2010), and more frequent hospitalisation (Eisner et al., 2010).

Recently, research has begun to expand beyond broad psychopathological constructs, such as depression and anxiety, into particular affective and cognitive processes that may influence how one attends and responds specifically to the symptom of dyspnea (Hallas,

Howard, Theadom, & Wray, 2012; Janssens et al., 2011). It has been proposed that breathlessness catastrophizing is one such cognitive process that warrants further investigation (Barrera, Grubbs, Kunik, & Teng, 2014; Livermore, Sharpe, & McKenzie, 2010a; Livermore, Sharpe, & McKenzie, 2012; McCathie et al., 2002).

Catastrophizing is an exaggerated negative cognitive orientation toward noxious stimuli and experiences, characterized by rumination about those experiences, magnification of their threat value, and perceived inability to control them (Sullivan, Bishop, & Pivik, 1995). It has been associated with measures of disability in other chronic medical conditions, particularly chronic pain (Kim et al., 2014; Kovacs et al., 2011; Lucey et al., 2011; Smeets, Vlaeyen, Kester, & Knottnerus, 2006; Wertli, Burgstaller et al., 2014) . In some studies of individuals with chronic pain, catastrophizing has been found to be more strongly correlated with disability than the pain itself (Crombez, Vlaeyen, Heuts, & Lysens, 1999; Helsen, Goubert, Peters, & Vlaeyen, 2011). This has contributed to the development of a fear-avoidance model of disability (Vlaeyen & Linton, 2000). The fear-avoidance model proposes that when a symptom is appraised as threatening, the individual may respond with fear, hypervigilance, and avoidance of activity that could trigger it. In the long term, these responses are counterproductive for rehabilitative efforts and can lead to further disability (Vlaeyen & Linton, 2000). Indeed, catastrophizing has been identified as a prospective marker of risk for severe disability in chronic pain (Kwon & Chang, 2013; Westman, Boersma, Leppert, & Linton, 2011), in part leading to the recommendation that the assessment and treatment of catastrophizing should be a regular part of patient care (Arnow et al., 2011; Hirsch, Bockow, & Jensen, 2011).

The conceptual link between catastrophizing and disability can perhaps be extended to other medical conditions that feature a prominent primary symptom. In the case of COPD, for

example, it would be expected that patients who catastrophize about dyspnea would similarly become fearful of, or hypervigilant to, the experience of breathlessness, perhaps leading to an avoidance of activities that might trigger shortness of breath (Boot, Heijmans, van der Gulden, & Rijken, 2008; Boot, van Exel, & van der Gulden, 2009; Simon et al., 2006). To date, however, speculation about the importance of catastrophizing in COPD has focused largely on its relevance to the emergence of panic symptomatology that occurs in some patients (Livermore et al., 2010a; Livermore, Sharpe, & McKenzie, 2010b).

More generally, a fear-avoidance model applied to COPD would suggest that individuals who catastrophize would engage in physical therapy at suboptimal levels and exhibit a more general unwillingness to engage in programs that are heavily focused on exercise (Janssens et al., 2011). However, there are limited options for assessing catastrophizing in individuals with COPD, so there has been little formal investigation of these hypotheses.

At present, the Interpretation of Breathing Problems Questionnaire (IBPQ) (Sutton, Cooper, Pimm, & Wallace, 1999) is the sole catastrophizing measure available for use with individuals with COPD. Its format makes it difficult to complete in a clinical setting, however, and it has seldom been used since its development in 1999 (Gurney-Smith, Cooper, & Wallace, 2002; Livermore, Sharpe, & McKenzie, 2007; Livermore, Sharpe, & McKenzie, 2008; Livermore et al., 2012). The IBPQ presents 14 scenarios (e.g., “You are in a smoky pub and your chest begins to feel tight.”) and asks respondents to answer qualitative questions that are subsequently scored by raters for degree of catastrophizing. IBPQ items have been found to correlate with measures of anxiety (Sutton et al., 1999), although not consistently (Gurney-Smith et al., 2002). Moreover, no studies have examined the association between IBPQ scores and functional measures. In the present study, the Breathlessness Catastrophizing Scale (BCS) is

proposed as an alternative measure offering several advantages. First, the BCS items directly reflect experiential aspects of catastrophizing (e.g., “There’s nothing I can do to reduce the intensity of the breathlessness”). Second, qualification as catastrophic thinking is not limited to an increase in anxiety, illness, or death. Third, the BCS is practical for clinical use, with each item requiring only a single quantitative rating. Finally, the BCS is a modification of the well-established Pain Catastrophizing Scale (PCS) (Sullivan et al., 1995), which represents the standard in the assessment of catastrophizing among patients with chronic pain.

Given the emerging focus on catastrophizing and anxiety-related concerns in COPD, the goals of the present study were to: (1) validate the scores on the BCS in a relatively large sample of patients undergoing pulmonary rehabilitation for COPD; (2) examine the relationship between breathlessness catastrophizing and measures of anxiety sensitivity, depression, self-efficacy, lung function, and performance in structured physical tasks; (3) examine whether breathlessness catastrophizing changes with participation in a pulmonary rehabilitation program; and (4) evaluate whether breathlessness catastrophizing is related to change in other rehabilitation outcomes. Specifically, we hypothesized that individuals with high levels of catastrophizing would show less improvement in psychological and physical function following interdisciplinary treatment.

Method

Participants

The study was approved by the Ottawa Health Science Network Research Ethics Board. Participants were 242 patients with COPD admitted to an inpatient, interdisciplinary pulmonary rehabilitation program at The Ottawa Hospital Rehabilitation Centre (TOHRC; Ottawa, Canada). In order to be eligible for admission to the program, patients had to be referred by a physician, 18

years of age or older, seeking to improve quality of life limited by shortness of breath, cognitively able to learn how to better manage the condition, and meet at least one of the following criteria: (1) $FEV_1 \leq 70\%$; (2) hospitalized recently or visited an emergency department due to dyspnea; (3) willing and able to initiate and maintain an exercise program; (4) using supplemental oxygen. Patients admitted to the program were included in this study if they had completed a BCS at admission.

Design

Chart reviews were conducted for eligible patients who participated in the program between 2007 and 2011. Extracted data included assessment of lung function, functional measures of exercise performance, and psychometric measures of catastrophizing, anxiety sensitivity, depression, and COPD self-efficacy. Measures completed at both program admission and discharge were collected.

Pulmonary Rehabilitation Program

Patients participated in a structured inpatient interdisciplinary pulmonary rehabilitation program based on GOLD and Canadian Thoracic Society guidelines (O'Donnell et al., 2007; Rabe et al., 2007). The program took place over four 5-day weeks, with patients returning home over weekends.

Measurements

Spirometry. Forced vital capacity (FVC) is the volume of air that can forcibly be exhaled after full inspiration, measured in litres. Forced expiratory volume in one second (FEV_1) is the volume of air that can be forcibly exhaled in one second, after full inspiration. These values were measured using a Profler and CPSF/D spirometer (Medical Graphic Corporation;

St. Paul, MN, US). Predicted values for these measurements (FVC%, FEV₁%) were based on reference values of pulmonary function tests of a Canadian sample (Gutierrez et al., 2004).

Exercise performance.

Six-Minute Walk Test. The Six-Minute Walk Test (6MWT) is the standard measure of functional capacity used in pulmonary and rehabilitation studies (ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories [ATS Committee], 2002). The test requires a 100-foot flat, hard surface on which individuals can walk unaccompanied. Patients are asked to walk as far as possible in six minutes, slowing, stopping, or resting, as needed. The primary outcome of interest is the distance walked. Contraindications include chest pain, intolerable dyspnea, leg cramps, staggering, diaphoresis, and pale or ashen appearance (ATS Committee, 2002). Contraindications were common in this sample, and only 98 patients (40%) completed the 6MWT at admission.

Non-Stop Walk Test. The Non-Stop Walk Test (NSWT) is an alternative measure used in the pulmonary rehabilitation program at TOHRC. In line with the findings of the developers of the 6MWT (Butland, Pang, Gross, Woodcock, & Geddes, 1982), longer intervals are considered preferable, when feasible. Patients are asked to walk for 20 minutes and are encouraged to use a comfortable, self-selected pace with slowing, but no pauses, rests or actual stops. Again, the primary outcome is the distance walked. All 242 patients completed this test at admission. For those 98 patients who completed both the 6MWT and the NSWT, the correlation between the two measures was $r = .74$.

Stair climbing. Stair climbing is a standard measure of functional capacity used in cardiac, pulmonary, and rehabilitation studies, and it is considered reflective of a primary activity of daily living and mobility (Brunelli et al., 2002). The present assessments required that the

patient climb as many steps as possible before having to stop because of dyspnea. The total number of stairs climbed was the primary outcome, with a maximum score of 49. All patients completed this test at admission.

Questionnaire measures.

Breathlessness catastrophizing. The BCS was adapted from the PCS (Sullivan et al., 1995) by replacing the term “pain” with “breathlessness,” where relevant. The resulting measure is a 13-item scale that asks respondents to rate “the degree to which you have these thoughts and feelings when you are experiencing breathlessness” (e.g., “I feel I can’t go on”; “It’s terrible and I think it’s never going to get any better”). Each item is rated on a five-point scale, ranging from 0 (*Not At All*) to 4 (*All The Time*). The original PCS has been found to have high test-retest reliability (Pearson’s $r = .92$) (Sullivan et al., 1995) and good internal consistency (Cronbach’s α s between .85 and .91) (Sullivan et al., 1995). The PCS has been found to have a moderate correlation with self-report measures of anxiety ($r = .32$) (Osman et al., 2000) and anxiety sensitivity ($r = .61$) (Kleiman, Clarke, & Katz, 2011).

Anxiety sensitivity. Anxiety sensitivity is the fear of physiological symptoms of anxiety due to the belief that they are harmful. Studies suggest that anxiety sensitivity promotes hypervigilance to bodily sensations and fearful interpretations of symptoms when they occur (Austin & Kiropoulos, 2008; Cox, 1996). Among patients with COPD, anxiety sensitivity has been found to predict greater dyspnea-related activity avoidance, even after controlling for diagnosed anxiety disorders and degree of pulmonary dysfunction (Simon et al., 2006). The Anxiety Sensitivity Index (ASI; Reiss, Peterson, Gursky, & McNally, 1986) is a 16-item self-report questionnaire that assesses individuals’ fear of anxiety-related symptoms. Each item is rated on a five-point scale, ranging from 0 (*Very Little*) to 4 (*Very Much*). Overall, the ASI has

very good construct validity (Reiss et al., 1986), internal consistency (Cronbach's α of .82-.91) (Peterson & Reiss, 1992), and test-retest reliability over a three-year period ($r = .71$) (Maller & Reiss, 1992). Cronbach's α for the current sample = .93 (average inter-item correlation = .45).

Depression. During the period of data collection, the respiratory rehabilitation program used two different measures of depression at different times. For part of the sample ($n = 124$), the 21-item Beck Depression Inventory-II (BDI-II; Beck, Steer, Ball, & Ranieri, 1996) was used to assess the presence and severity of depressive symptoms. Responses to each item are rated on a 4-point scale, ranging from 0 to 3, with higher scores reflecting more severe symptomatology. The BDI-II has been found to have high internal consistency ($\alpha = .91$) (Beck et al., 1996), as well as good convergent validity when correlated with other measures of depression. Cronbach's α for the current sample = .88 (average inter-item correlation = .27). For the rest of the sample ($n = 118$), depressive symptoms were assessed using the 9-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001). On this measure, respondents rate how often they have been bothered by each of several diagnostically relevant symptoms. Responses are recorded on a 4-point scale, ranging from 0 (*Not At All*) to 3 (*Nearly Every Day*). The PHQ-9 has demonstrated excellent internal consistency (Cronbach's $\alpha = .86-.89$) and test-retest reliability ($r = .84$) (Kroenke, et al., 2001). Cronbach's α for the current sample = .87 (average inter-item correlation = .33).

COPD self-efficacy. The COPD Self-Efficacy Scale (CSES; Wigal, Creer, & Kotses, 1991) is a 34-item self-report questionnaire that assesses individuals' perceived confidence in their ability to manage or avoid breathing difficulties in various situations. Each item is rated along a five-point scale, ranging from 1 (*Very Confident*) to 5 (*Not At All Confident*). An overall measure of self-efficacy can be derived as a total score, with higher scores reflecting lower self-

efficacy. Internal consistency (Cronbach's α of .95) and test-reliability ($r = .77$) were reported to be satisfactory (Wigal et al., 1991). Cronbach's α for the current sample = .96 (average inter-item correlation = .42).

Data Analysis

Data were screened using Tabachnick and Fidell's recommended procedures (2007). Error checks verified the accuracy of the data. Three patients had no BCS in their charts, and so were excluded listwise. No outliers were detected. All measures passed assessments of normality, with the exception of the BCS, which demonstrated a positive skew. As the central variable of interest, no transformations or other adjustments were performed. Multicollinearity was not detected.

Statistical analyses consisted of five distinct parts. First, comparisons were undertaken between program completers and non-completers, using chi-square analyses for categorical measures and independent samples *t*-tests for continuous ones. Second, for initial construct validation of the BCS, a principal components analysis (PCA) was conducted to examine the underlying factor structure of the catastrophizing items. PCA is considered to provide the best explanation of data variance without requiring a priori assumptions about the nature of the factor structure (Tabachnick & Fidell, 2007). Third, to assess the relationship between breathlessness catastrophizing and other baseline measures, a series of bivariate correlations were examined. Fourth, to identify the extent of change in breathlessness catastrophizing and other measures following pulmonary rehabilitation, data collected from program completers at admission and discharge were compared using paired-samples *t*-tests. Fifth, subgroups were created based on BCS scores at admission. Clinically, BCS scores are likely to be most informative for identifying individuals who are highly prone to catastrophizing. Hence, we selected patients in the upper

quartile of BCS scores and compared them with all others in the sample (Wertli, Eugster et al., 2014). Admission and discharge scores were compared using 2 (Group) X 2 (Time) Analyses of Variance (ANOVA). No control variables were used. All analyses were conducted using SPSS version 20. Significance was set at $p < .05$.

Results

Sample Characteristics

Of the 242 patients ($n = 126$ women, 52%), most had very severe (Stage IV: $n = 140$, 58%) or severe (Stage III: $n = 70$, 29%) COPD, based on FEV₁ percent predicted staging (GOLD, 2013). Baseline characteristics of the sample are provided in Table 1. Fifty-six patients (23%) did not complete the program. No significant differences were demonstrated between treatment completers and non-completers.

Validation of the BCS

Item-level analysis. Although individual distributions varied across items, each value on the 5-point scale was used for all 13 items. The mean, standard deviation, and item-total correlation for each question on the BCS are presented in Table 2. Notably, there were no negative item-total correlations. Therefore, no item detracted from the cohesiveness of the total BCS scale. Across the 13 items, Cronbach's alpha was .96 (average inter-item correlation = .64), demonstrating excellent internal consistency.

The average total score was 18.25 ($SD = 11.76$), and the score distribution ranged from 0 to 52, the lowest and highest scores possible. There were seven individuals with scores of 0, suggesting no breathlessness catastrophizing in less than 3% of program participants. The overall average item rating on the 13-item scale was 1.44, which falls between "slight" and "moderate" agreement. Question 8 ("I anxiously want the breathlessness to go away") was the most highly

rated ($M = 2.05$, $SD = 1.31$) whereas question 5 (“I feel I can’t stand it anymore”) was rated lowest ($M = 1.09$, $SD = 1.19$).

Factor analysis. No constraints were placed on the principal components analysis. The eigenvalue for the first principal component was 8.74, declining sharply to 0.75 for the second. This suggested a one component structure. All items loaded on this single component, with loadings ranging from .73 to .88 (see Table 2).

Relationships Between Breathlessness Catastrophizing and Other Study Variables

Demographics. Bivariate correlations of BCS with gender and age revealed no significant relationships.

Psychological variables. At program admission, BCS scores were moderately and positively correlated with anxiety sensitivity, depressive symptomatology, as measured by either the BDI-II or the PHQ-9, and scores on the CSES, indicating lower sense of self-efficacy at managing or avoiding breathing difficulty (see Table 3).

Respiratory function. At baseline only FVC% correlated with BCS scores. Although statistically significant, the correlation was small in magnitude ($r = -.19$, $p = .004$). There was no association between BCS scores and prescribed oxygen.

Exercise performance. Breathlessness catastrophizing was not significantly correlated with the baseline measures of exercise performance (all $ps > .10$). However, both walk tests and the stairs exercise were correlated significantly with one another ($ps < .01$) and with the FVC%. In addition, performance on the 6MWT was correlated significantly with the FEV₁%.

Outcome of Pulmonary Rehabilitation

The pre- and post-rehabilitation scores for all measures of respiratory function, exercise performance, and psychological variables are shown in Table 4. From admission to discharge,

spirometry did not reveal any significant change in lung function, $ps > .05$. However, patients improved on all measures of physical and psychological functioning, including scores on the BCS, $p \leq .001$. The change in BCS scores approaches a medium effect size, $d = .43$ (Cohen, 1992).

Group Comparisons Based On BCS Scores at Admission

To examine the clinical relevance of the BCS for rehabilitation in COPD, the subgroup of participants who fell in the upper quartile of BCS scores at admission was compared with the rest of the sample. The scores are shown in Figure 1. In addition to the main effect of group, $F(1,184) = 138.61$, $p < .001$, $h_p^2 = .47$, these scores showed a significant main effect of time, $F(1,184) = 82.17$, $p < .001$, $h_p^2 = .34$, indicating an overall decrease following rehabilitation. The Group X Time interaction was also significant, $F(1, 184) = 39.43$, $p < .001$, $h_p^2 = .20$, with a large decrease occurring in the high-scoring BCS group. However, this group still had higher scores at discharge than the rest of the sample.

As shown in Figure 1, a main effect of time was demonstrated for each of the psychological measures: ASI, $F(1, 184) = 12.80$, $p < .001$, $h_p^2 = .08$; BDI-II, $F(1, 93) = 43.75$, $p < .001$, $h_p^2 = .41$; PHQ-9, $F(1, 89) = 28.98$, $p < .001$, $h_p^2 = .30$; and CSES, $F(1, 184) = 40.99$, $p < .001$, $h_p^2 = .32$, as was a significant group main effect for the ASI, $F(1, 184) = 39.31$, $p < .001$, $h_p^2 = .20$; PHQ-9, $F(1, 89) = 6.23$, $p = .015$, $h_p^2 = .08$; and CSES, $F(1, 184) = 6.66$, $p = .012$, $h_p^2 = .07$. In each case, participants in the upper quartile BCS group had higher scores, both at admission and discharge. Although no significant group main effect was demonstrated with the BDI-II, a trend was observed, $p = .094$, as was a significant interaction, $F(1, 93) = 5.73$, $p = .02$, $h_p^2 = .09$. Patients in the upper quartile of BCS scores had higher BDI scores at admission, but

not at discharge. This was not replicated with the participants who had completed the PHQ-9.

On the functional measures, there were significant improvements over time for the 6MWT, $F(1, 90) = 14.61, p < .001, h_p^2 = .14$; NSWT, $F(1, 184) = 134.88, p < .001, h_p^2 = .37$ and stairs test, $F(1, 184) = 59.86, p < .001, h_p^2 = .23$, but no significant group effects, $ps > .05$. However, a significant Group X Time interaction was found with the stairs test, $F(1, 184) = 3.88, p = .05, h_p^2 = .02$. An independent samples *t*-test of change scores revealed that, on average, participants in the upper quartile BCS group showed a significantly greater degree of improvement on the stairs, $t(240) = 1.97, p = .05$.

Discussion

The first goal of this study was to validate the BCS, a measure of breathlessness catastrophizing derived from the widely used PCS (Sullivan et al., 1995) for pain research, with a relatively large sample of patients undergoing pulmonary rehabilitation for COPD. The results indicated that the BCS consists of a single factor, to which all 13 items contribute, and yields a scale with excellent internal consistency.

It is noteworthy that the BCS comprises a single factor, which is different than the three-factor structure of rumination, magnification, and helplessness that characterizes the PCS in chronic pain (Sullivan et al., 1995). Whereas some other studies have demonstrated a one-factor structure to the PCS (Osman et al., 2000), and most focus on the total score, the contrasting factor structures of the BCS and PCS suggest that there may be differences in the underlying phenomenon of catastrophizing when an individual is experiencing breathlessness, rather than pain.

The second goal was to examine the relationship between breathlessness catastrophizing and measures of anxiety sensitivity, depression, self-efficacy, lung function, and exercise

performance. Analyses of the baseline data showed that the BCS was correlated with the other self-report measures of psychological constructs. With regard to respiratory measures, the BCS showed a weak correlation with the FVC, but did not correlate significantly with the FEV₁. Finally, the BCS did not correlate significantly with the baseline measures of exercise performance. Overall, therefore, the BCS shows convergent validity in its associations with other measures of psychological distress, but has the advantage of specificity to the cognitive reaction of dyspnea. Therefore, it is of more direct relevance to the experience of patients with COPD.

In contrast to the present findings, others have reported that constructs pertaining more directly to psychopathology, such as anxiety, panic and depression, do correlate with functional measures (Eisner et al., 2010; Giardino, Curtis, Abelson et al., 2010; Giardino, Curtis, Andrei et al., 2010; Livermore et al., 2010a; Livermore et al., 2010b; Ng et al., 2007). One possible explanation is that those findings reflect more severe psychological disorders. For example, fatigue and psychomotor retardation are symptoms of depressive disorders that could impair exercise performance (Buyukdura, McClintock, & Croarkin, 2011), but are not addressed by the more cognitive focus on catastrophizing. Similarly, the experience of panic may have more pervasive functional consequences.

In addition, different studies have assessed functional performance in different ways. Self-reports of function may reflect common method variance with self-reports of psychological states, perhaps inflating the correlations when compared to performance-based measures. Indeed, many previous studies have used a self-report format for assessing function (Alexopoulos et al., 2006; Bratås, Espnes, Rannestad, & Walstad, 2012; Simon et al., 2006).

It should also be noted that structured performance tasks, while important for assessing outcome in a standardized way, may not provide the optimal protocol for demonstrating the role

of cognitive processes in COPD. Catastrophic concerns about breathlessness may be more evident in self-selected activities in which avoidance is an option, rather than in supervised therapeutic tasks that place a high priority on patient safety. If so, then decisions about participating in, or avoiding, an activity, and the confidence versus fearfulness with which one engages in it, may be more closely related to catastrophizing than performance measures achieved under supervision. The significant correlation between scores on the BCS and the CSES offers some support for this possibility. On the other hand, neither BCS scores nor any other measure predicted program withdrawal, which could be construed as a form of avoidance for some patients. In general, therefore, there was no clear evidence from the baseline data of an association between catastrophizing and functional performance. Future research could consider such issues as engagement in the rehabilitation process and naturalistic studies of participation in self-selected activities.

The final goal of the study was to examine change over time following pulmonary rehabilitation. In this context, the results indicated that BCS scores, as well as other psychological measures, improved significantly following participation in the program. There were also reliable improvements in the measures of exercise performance. Moreover, the analyses focusing on the participants in the highest quartile of BCS scores did suggest an association between catastrophizing and functional progress with rehabilitation. On the stair-climbing test, the high catastrophizing patients had more pronounced improvement from pre- to post-treatment, although comparisons at either time point alone did not differ between the groups. This finding offers tentative support for the hypothesis that catastrophizing may be related to participation in the process of rehabilitation. Nevertheless, it should be noted that this conclusion is based on a small effect on a single measure of functional outcome. Therefore, it

requires confirmation in future research. More generally, however, it appears evident from the present study that catastrophizing is not a barrier to functional change; even those with the highest levels of breathlessness catastrophizing can make meaningful functional gains with interdisciplinary pulmonary rehabilitation.

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Table 1
Baseline Characteristics of Patients

Characteristic	Total sample (N = 242)				Completers (n = 186)				Non-completers (n = 56)			
	M	SD	n	%	M	SD	n	%	M	SD	n	%
Age (years)	66.1	11.2			65.8	10.7			67.0	13.2		
Sex												
Female			126	52.1			101	54.3			24	42.9
Male			116	47.9			85	45.7			32	57.1
FEV ₁ , % predicted	41.0	19.5			41.5	19.9			39.3	18.2		
FVC, % predicted	60.7	18.6			61.3	19.0			58.7	17.3		
COPD severity												
Stage I			0	0.0			0	0.0			0	0.0
Stage II			32	13.2			24	12.9			8	14.3
Stage III			70	28.9			52	28.0			18	32.1
Stage IV			140	57.9			110	59.1			30	53.6
Oxygen prescription			58	24.0			45	24.2			13	23.2
6MWT, m ^a	311.9	92.6	98 ^a		308.7	89.9	92 ^a		326.1	105.4	6 ^a	
NSWT, m	447.9	363.6			451.7	360.1			435.4	378.2		
Stairs, steps	20.1	13.7			19.7	13.2			21.6	15.6		
BCS	18.2	11.8			18.7	12.2			17.0	10.2		
ASI	21.7	11.6			22.3	11.9			19.6	10.3		
BDI-II ^b	12.0	7.7	124 ^b		11.4	7.6	95 ^b		14.1	7.7	29 ^b	
PHQ-9 ^b	5.7	4.7	118 ^b		5.7	4.2	91 ^b		5.5	6.2	27 ^b	
CSES	106.7	14.2			106.2	14.7			108.2	12.4		

Note. FEV₁ = forced expiratory volume in one second; FVC = forced vital capacity; 6MWT = Six-Minute Walk Test; NSWT = Non-Stop Walk Test; BCS = Breathlessness Catastrophizing Scale; ASI = Anxiety Sensitivity Index; BDI-II = Beck Depression Inventory-II; PHQ-9 = 9-Item Patient Health Questionnaire; CSES = COPD Self-Efficacy Scale.
^aDue to clinical considerations not all patients completed the 6MWT. ^bDuring the period of data collection, the program used two different measures of depression at different times. Therefore patients received either the BDI-II or the PHQ-9.

Table 2

Item-Level Analysis and Principal Component Loadings of the Breathlessness Catastrophizing Scale Items

Breathlessness Catastrophizing Scale Items	<i>M</i>	<i>SD</i>	Item-Total Correlation	Component Loading
1. I worry all the time about whether the breathlessness will subside.	1.48	1.14	0.74	0.78
2. I feel I can't go on.	1.13	1.15	0.75	0.79
3. It's terrible and I think it's never going to get any better.	1.40	1.26	0.85	0.88
4. It's awful and I feel that it overwhelms me.	1.36	1.24	0.86	0.88
5. I feel I can't stand it anymore.	1.09	1.19	0.81	0.84
6. I become afraid that the breathlessness will get worse.	1.78	1.28	0.82	0.85
7. I keep thinking of other times I have been breathless.	1.23	1.22	0.71	0.75
8. I anxiously want the breathlessness to go away.	2.05	1.31	0.76	0.79
9. I can't seem to keep it out of my mind.	1.21	1.22	0.80	0.83
10. I keep thinking about how out of breath I am.	1.34	1.19	0.77	0.80
11. I keep thinking about how badly I want the breathlessness to stop.	1.68	1.34	0.83	0.86
12. There's nothing I can do to reduce the intensity of the breathlessness.	1.29	1.17	0.69	0.73
13. I wonder whether something serious might happen.	1.64	1.34	0.83	0.86

Note. Cronbach's alpha = .96 (average inter-item correlation = .64). Item ratings ranged from 0 ("Not At All") to 4 ("All The Time".)

Table 3

Correlations Between Measures at Baseline

	BCS	ASI	BDI-II ^a	PHQ-9 ^a	CSES	FEV ₁ %	FVC%	6MWT ^a	NSWT
BCS	-								
ASI	.61***	-							
BDI-II ^a	.50***	.52***	-						
PHQ-9 ^a	.42***	.51***	^b	-					
CSES	.34***	.30***	.36***	.19	-				
FEV ₁ %	-.12	.06	-.01	.05	-.04	-			
FVC%	-.19**	-.08	-.25*	.13	-.09	.60***	-		
6MWT ^a	-.15	-.06	.07	-.28	.15	.29**	.30**	-	
NSWT	-.11	-.05	-.07	-.09	.02	.12	.19**	.61***	-
Stairs	-.10	-.12	-.09	-.11	-.02	.03	.21**	.43***	.56***

Note. $N = 242$. BCS = Breathlessness Catastrophizing Scale; ASI = Anxiety Sensitivity Index; BDI-II = Beck Depression Inventory-II; PHQ-9 = 9-Item Patient Health Questionnaire; CSES = COPD Self-Efficacy Scale; FEV₁% = forced expiratory volume in one second, % predicted; FVC% = forced vital capacity, % predicted; 6MWT = Six-Minute Walk Test; NSWT = Non-Stop Walk Test.

^aDue to program and clinical considerations not all patients completed all measures included here: BDI-II ($n = 124$); PHQ-9 ($n = 118$), 6MWT ($n = 98$). ^bDuring the period of data collection, the program used two different measures of depression at different times. Therefore patients received either the BDI-II or the PHQ-9.

* $p < .05$, two-tailed. ** $p < .01$, two-tailed. *** $p < .001$, two-tailed.

Table 4

Change in Outcome Measures from Admission to Discharge

Variable	Admission		Discharge		Change			
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>d</i> ^b	95% CI
FEV ₁ , % predicted	41.85	20.16	42.67	20.81	1.16	.248	0.04	-0.16, 0.24
FVC, % predicted	62.08	18.15	62.42	18.12	0.35	.725	0.02	-0.18, 0.22
6MWT, m ^a	313.04	94.42	344.68	85.75	4.48	<.001	0.35	0.06, 0.64
NSWT, m	447.59	362.19	677.50	293.52	12.87	<.001	0.70	0.49, 0.91
Stairs, steps	20.24	14.12	26.68	19.04	7.65	<.001	0.38	0.18, 0.59
BCS	18.13	11.70	13.30	11.50	-6.14	<.001	0.42	0.21, 0.62
ASI	21.85	12.21	18.85	13.06	-3.33	.001	0.24	0.03, 0.44
BDI-II ^a	11.25	7.76	6.70	6.47	-6.08	<.001	0.64	0.34, 0.93
PHQ-9 ^a	5.76	4.23	2.68	3.32	-6.41	<.001	0.81	0.50, 1.11
CSES	104.43	18.37	84.02	28.79	-7.31	<.001	0.85	0.63, 1.06

Note. *n* = 186. FEV₁ = forced expiratory volume in one second; FVC = forced vital capacity;

6MWT = Six-Minute Walk Test; NSWT = Non-Stop Walk Test;

BCS = Breathlessness Catastrophizing Scale; ASI = Anxiety Sensitivity Index;

BDI-II = Beck Depression Inventory-II; PHQ-9 = 9-Item Patient Health Questionnaire;

CSES = COPD Self-Efficacy Scale.

^aDue to clinical and program considerations not all patients completed all measures included here: 6MWT (*n* = 92); BDI-II (*n* = 95); PHQ-9 (*n* = 91). ^b*d* = Cohen's *d* where .20, .50, and .80 represent small, medium and large effects, respectively.

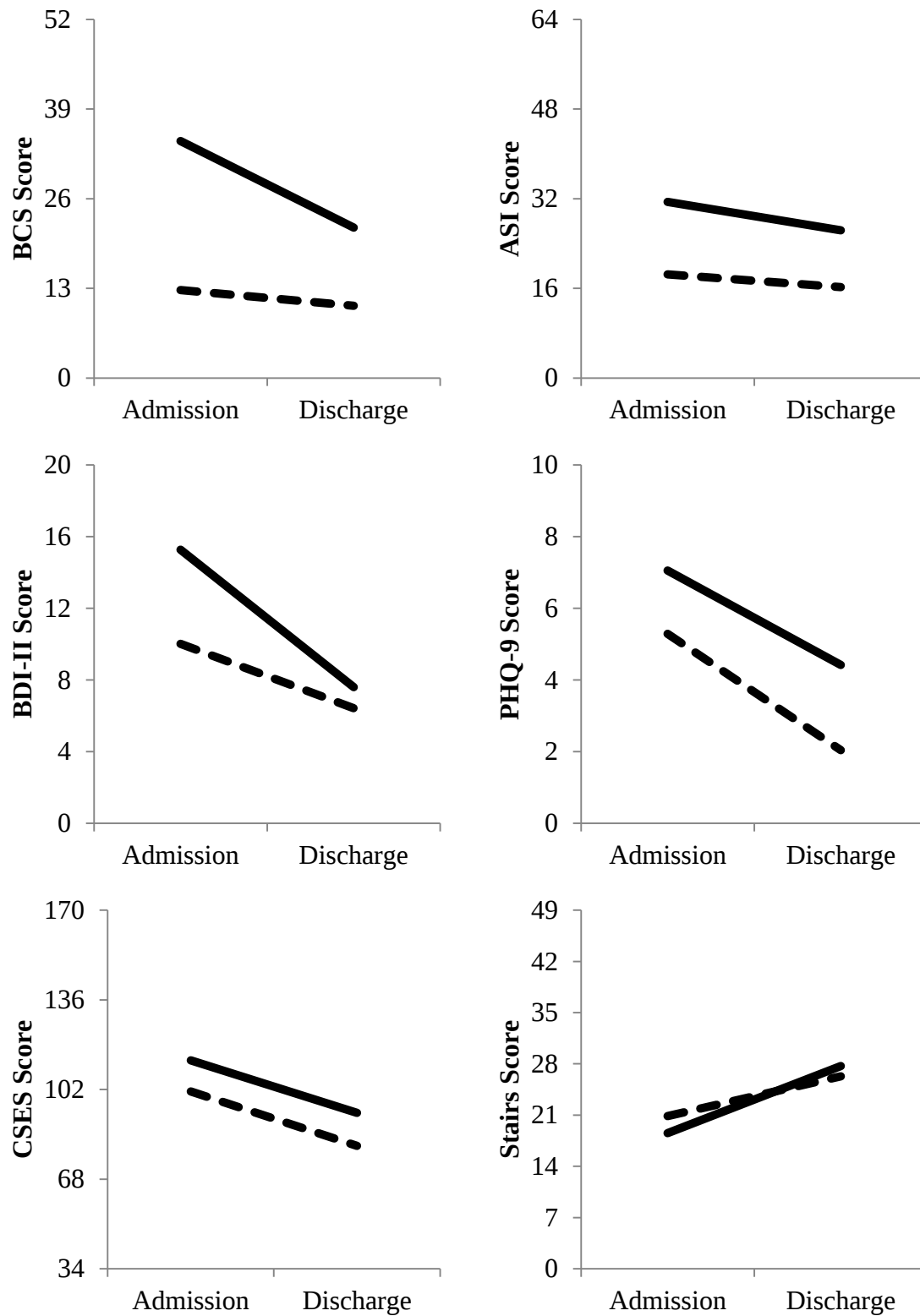


Figure 1.

Figure 1. Admission and discharge scores by time and BCS group. Solid lines represent the upper quartile BCS group; dashed lines represent the rest of the sample. (BCS = Breathlessness Catastrophizing Scale, ASI = Anxiety Sensitivity Scale, BDI-II = Beck Depression Inventory-II, PHQ-9 = 9-Item Patient Health Questionnaire, CSES = COPD Self-Efficacy Scale; BCS, ASI, CSES, Stairs: $n = 186$; BDI-II: $n = 95$; PHQ-9: $n = 91$.)

Chapter 3

- Study 2 -

“Loss of Dignity in Severe Chronic Obstructive Pulmonary Disease”

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Loss of Dignity in Severe Chronic Obstructive Pulmonary Disease

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Abstract

Context: The maintenance of dignity is an important concept in palliative care, and the loss of dignity is a significant concern among patients with advanced cancer. *Objectives:* The goals of this study are 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. *Methods:* Inpatients underwent a structured interview inquiry around their sense of dignity, and completed measures of pulmonary, physical, and psychological function at admission ($n = 195$) and discharge ($n = 162$). *Results:* Loss of dignity was identified as a prominent ongoing concern for 13% of patients. It was correlated with measures of depression, anxiety sensitivity, and breathlessness catastrophizing, but not with pulmonary capacity or functional performance. A robust improvement in problematic loss of dignity was demonstrated, with 88% of those who reported a significant problem at admission no longer reporting one at discharge. *Conclusion:* The prevalence of a “fractured” sense of dignity among patients with severe COPD is at least as high as among those receiving palliative cancer care. Loss of dignity may represent a concern among people with medical illnesses more broadly, and not just in the context of “death with dignity” at the end-of-life. Further, interdisciplinary care may help to reduce loss of dignity for those individuals who are able to participate in rehabilitation.

Keywords: loss of dignity, chronic obstructive pulmonary disease, rehabilitation, depression, anxiety

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the U.S. and the sixth leading cause of years lived with disability (US Burden of Disease Collaborators, 2013). For those with established COPD, the recommended treatment includes interdisciplinary rehabilitation, an intervention that incorporates education about illness self-management and enhancement of functional performance (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2013; Róman et al., 2013; Rubí et al., 2010; Tselebis et al., 2013; van Ranst, Otten, Meijer, & van t' Hul, 2011). Even with rehabilitation, however, COPD is not curable and the underlying airways disease is generally irreversible.

Although there is evidence that those with severe COPD could also benefit from palliative care (Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009; Elkington, White, Addington-Hall, Higgs, & Pettinari, 2004; Habraken, Willems, de Kort, & Bindels, 2007; Higginson et al., 2014), frameworks for its implementation are not well-explored. Some investigators have suggested that models developed for patients with cancer represent a reasonable starting point for considerations of palliative care in COPD (Bausewein et al., 2010). Where this has been done, studies have found that the symptom profile of COPD overlaps with that of lung cancer. Breathlessness is a common primary symptom, followed by drowsiness, lack of energy, and cough (Bausewein et al., 2010). Although the prognosis of patients with severe COPD is less certain than for those with advanced cancer (Curtis, 2008), patients with Stage III and IV COPD survive nearly five times as long, on average. Thus, palliative care needs are likely to arise earlier in the disease trajectory (Blinderman et al., 2009) and patients must cope with their situation much longer (Bausewein et al., 2010).

One unique aspect of palliative care is an emphasis on existential concerns. Although prominent existential crises are not universal among the terminally ill (Cherny, 2010; Chochinov et al., 2002; Chochinov et al., 2006; de Faye, Wilson, Chater, Viola, & Hall, 2006; LeMay & Wilson, 2008; Thompson et al., 2009; Wilson et al., 2009; Yamagishi et al., 2012), when they do arise they can be so significant that even physical symptoms are considered secondary in comparison (Breitbart et al., 2000; Chochinov, Tataryn, Clinch, & Dudgeon, 1999). Among existential sources of suffering, the loss of dignity has emerged as a central consideration in palliative care, as is reflected in the popular term “death with dignity.” Although the preservation of dignity is valued highly in the context of life-threatening illness, few studies have actually examined concerns about dignity from an empirical perspective (Chochinov et al., 2002; Chochinov et al., 2006; de Faye et al., 2006; Wilson, Chochinov, Skirko et al., 2007; Wilson et al., 2004). This small body of research has found that the majority (54-75%) of patients receiving palliative care for cancer report no loss of dignity, with another 15-40% reporting a minor loss. Only 5-10% of patients report that loss of dignity is a clinically significant and ongoing concern, which Chochinov et al. (2002) have described as a “fractured” sense of dignity. Importantly, however, these individuals report more difficulties with self-care activities, and are more likely to report feeling depressed and anxious, and to regard themselves as having become a burden to others (Chochinov et al., 2002).

The disability caused by COPD, and its symptomatic comparability to lung cancer, suggest that the loss of dignity may also be a concern for this population. On the other hand, the longer survival expectancy with COPD and the emphasis on active rehabilitation indicate that the study of dignity could perhaps be broadened beyond an explicit focus on the end of life. In addition, there is no evidence as to whether a fractured sense of dignity is amenable to change with

appropriate intervention, as might occur with rehabilitation. These issues represent the main objectives of this study: (1) to examine whether loss of dignity is a relevant construct in COPD, by identifying its prevalence and correlates among individuals with severe airways disease, and (2) to examine whether the loss of dignity changes with pulmonary rehabilitation.

Methods

Participants

Study participants were 195 inpatients with Stage III (severe) or IV (very severe) COPD who were admitted to a pulmonary rehabilitation program. Program admission required referral by physician, being 18 years of age or older, and at least one of the following criteria: (1) recent hospitalization or emergency visit due to dyspnea; (2) seeking improvement to quality of life affected by dyspnea; (3) FEV₁ between 15 and 70% of predicted values; (4) supplemental oxygen use.

Design

Hospital records were reviewed for data concerning pulmonary, physical, and psychological function, both at program admission and discharge. Chart reviews included all eligible patients from 2007 to 2011, with approval from the Ottawa Health Science Network Research Ethics Board.

Program

The program was a structured interdisciplinary pulmonary rehabilitation program based on GOLD and Canadian Thoracic Society guidelines (O'Donnell et al., 2007; Rabe et al., 2007). Patients were seen as inpatients over the course of four 5-day weeks by clinicians from a range of rehabilitation disciplines, including respirologists, clinical dietitians, nurses, occupational therapists, psychologists, physiotherapists, respiratory therapists, and social workers.

Measurements

Pulmonary.

Spirometry. Spirometric measures included the forced expiratory volume in one second (FEV₁) and forced vital capacity (FVC), which represent exhalation volumes in the first second after full inhalation and after complete exhalation. A Profiler and CPSF/D spirometer (Medical Graphic Corporation; St. Paul, MN, US) was used, in conjunction with a Canadian reference sample (Gutierrez et al., 2004) as the basis for predicted values (FVC%, FEV₁%).

Functional.

Exercise performance.

Six-Minute Walk Test. The Six-Minute Walk Test (6MWT) is the standard measure of functional capacity used in pulmonary and rehabilitation studies (American Thoracic Society Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories [ATS Committee], 2002). Patients walk unaccompanied for a period of six minutes on a flat 30-meter surface, while distance is measured. Although slowing or resting is permitted, symptoms of chest pain, intolerable dyspnea, staggering, or pale or ashen appearance are contraindications for continuation of this test (ATS Committee, 2002). As contraindications were prevalent in this sample, only 66 patients completed the 6MWT at admission.

Non-Stop Walk Test. The Non-Stop Walk Test (NSWT) is an alternative measure of functional capacity used with patients for whom the 6MWT is contraindicated. Patients are asked to walk for twenty minutes at a self-selected pace without pauses, rests or stops, while distance covered is measured. All 195 patients completed the NSWT at admission.

Stair climbing. Stair climbing represents an important activity of daily living and can be used as a standard measure of functional capacity (Brunelli et al., 2002). Patients are asked to

climb as many stairs as possible, stopping when dyspnea becomes prohibitive. The number of stairs climbed is recorded, with a maximum score of 49.

Self-report measures.

Breathlessness catastrophizing. The Breathlessness Catastrophizing Scale (BCS; Solomon et al., 2015) is a new 13-item self-report questionnaire that assesses the tendency to ruminate about dyspnea, magnify its threat value, and feel helpless when experiencing it. For each item, the respondent is asked to rate “the degree to which you have these thoughts and feelings when you are experiencing breathlessness” (e.g., “It’s terrible and I think it’s never going to get any better”; “It’s awful and I feel that it overwhelms me”). Each statement is rated on a five-point scale, ranging from 0 (*Not At All*) to 4 (*All The Time*). The BCS has excellent internal consistency and has been found to have moderate-to-strong correlations with self-report measures of anxiety sensitivity and depression (Solomon et al., 2015). Data from participants in the present study were also used in the validation of the BCS.

Anxiety sensitivity. The Anxiety Sensitivity Index (ASI; Reiss, Peterson, Gursky, & McNally, 1986) is a 16-item self-report questionnaire that assesses individuals’ fear of sensations associated with anxiety. The ASI has good construct validity (Reiss et al., 1986), internal consistency (Peterson & Heilbronner, 1987; Peterson & Reiss, 1992), and test-retest reliability (Maller & Reiss, 1992). It has been used in previous studies examining patients with COPD, for whom it is relevant to the anxiety associated with breathlessness (Giardino et al., 2010; Livermore, Sharpe, & McKenzie, 2007; Livermore, Sharpe, & McKenzie, 2008; Livermore, Sharpe, & McKenzie, 2012).

Depression. Two measures of depression were included, due to a change in the evaluation protocol used in the pulmonary rehabilitation program during the course of data

collection. Initially ($n = 106$), depressive symptoms were assessed with the Beck Depression Inventory-II (BDI-II; Beck, Steer, Ball, & Ranieri, 1996). This 21-item questionnaire uses a 4-point scale for item responses, with higher scores reflecting more severe depressive features. The Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was used with the remaining patients ($n = 89$). This 9-item measure asks respondents to rate how often they are bothered by specific symptoms that are diagnostic for depressive disorders in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000). Each symptom is rated on a 4-point scale, with higher scores indicating greater frequency of occurrence over the previous two weeks. Both the BDI-II and PHQ-9 have excellent internal consistency and diagnostic validity, and are used widely in health research (Beck et al., 1996; Löwe et al., 2004; Segal, Coolidge, Cahill, & O'Riley, 2008).

COPD self-efficacy. The COPD Self-Efficacy Scale (CSES; Wigal, Creer, & Kotses, 1991) is a 34-item questionnaire that assesses individuals' perceived ability to manage breathing difficulties in a variety of situations in which individuals with COPD typically experience dyspnea. The five-point rating scale ranges from 1 (*Very Confident*) to 5 (*Not At All Confident*). The respondent's total score represents his or her self-efficacy, with lower scores indicating greater levels of confidence. Good internal consistency and test-reliability have been reported (Wigal et al., 1991).

Self-perceived burden. The Self-Perceived Burden Scale (SPBS; Cousineau, McDowell, Hotz, & Hébert, 2003) is a 10-item questionnaire that assesses the frequency with which an individual feels a sense of being an emotional, instrumental, or financial burden to primary caregivers. Responses are rated along a five-point scale, ranging from 1 (*None of the Time*) to 5 (*All of the Time*). Internal consistency is good among patients with various health conditions,

including kidney failure (Cousineau et al., 2003), cancer (McPherson, Wilson, Lobchuk, & Brajtman, 2007), stroke (McPherson, Wilson, Chyurlia, & Leclerc, 2010), and chronic pain (Kowal, Wilson, McWilliams, Péloquin, & Duong, 2012). Chochinov et al. found that a prominent sense of self-perceived burden was a unique correlate of loss of dignity (2002) and one of the most frequently endorsed dignity-related concerns (2006) in patients receiving palliative care for cancer.

Interview.

Loss of dignity. Each participant was interviewed individually at program admission and discharge by a clinical psychologist or psychology intern. The interviews were conducted as part of a clinical assessment, and included the loss of dignity item (LoDi) from the Structured Interview for Symptoms and Concerns (SISC; Wilson et al., 2004). With this measure, a structured introductory lead question asks, “Do you feel that you are able to maintain your dignity and self-respect?” If the respondent acknowledges any loss of dignity, the severity of the problem is reviewed using a series of follow-up prompts (e.g., “Do your medical problems make you feel ashamed, degraded, or embarrassed?” “Do you feel devalued as a person?”). Patients are then asked if the loss of dignity is regarded as a significant ongoing problem. The interviewer rates the global severity of concerns about loss of dignity on a 7-point scale ranging from 0 (*No Loss of Dignity*) to 6 (*Extreme*). Scores ≥ 3 correspond to the participant acknowledging loss of dignity as a “generally significant problem,” and represents the threshold for identifying a concern as being potentially important for clinical care. Chochinov et al. (2002) used LoDi scores in this range to identify individuals who experienced a fractured sense of dignity. The LoDi interviewer assessment shows a strong correlation with patients’ visual analogue scale ratings of loss of dignity; it also has excellent inter-rater reliability (Wilson et al., 2004). The

SISC LoDi has been used in several previous studies of patients receiving palliative care for cancer (Chochinov et al., 2002; de Faye et al., 2006; Houmann, Chochinov, Kristjanson, Petersen, & Groenvold, 2014; Wilson, Chochinov, Skirko et al., 2007; Wilson et al., 2004).

Data Analysis

Data were screened using Tabachnick and Fidell's recommended procedures (2007). Error checks verified the accuracy of the data. Fifteen patients had no LoDi scores in their charts, so were excluded listwise. No outliers were detected. All measures passed assessments of normality, with the exception of the LoDi and the BCS, which demonstrated positive skews. As central variables of interest, no transformations or other adjustments were performed. Multicollinearity was not detected.

Statistical analyses consisted of five distinct parts. First, comparisons were undertaken between program completers and non-completers, using chi-square analyses for categorical measures and independent samples *t*-tests for continuous ones. Second, to determine the prevalence of fractured dignity among those with severe COPD, the distribution of LoDi scores at admission was examined. Third, to assess the relationship between loss of dignity and other baseline measures, a series of bivariate correlations was examined. Fourth, subgroups were created based on loss of dignity grouping (i.e., intact or fractured) at admission. Admission and discharge scores were then compared using 2 (Group) X 2 (Time) Analyses of Variance (ANOVA). Fifth, to identify whether any patients with fractured dignity at admission reported an intact sense of dignity at discharge, a McNemar's test was performed. This test was also used to verify whether any patients declined from an intact to a fractured sense of dignity over the course of the program. No control variables were used. All analyses were conducted using SPSS version 20. Significance was set at $p < .05$.

Results

Sample Characteristics

A total of 195 patients ($n = 88$ women, 45%) were assessed at baseline. Their demographic characteristics are shown in Table 1. Thirty-three patients (17%) did not complete the program. No significant differences were demonstrated between treatment completers and non-completers. Analyses using admission data were carried out on the total sample ($n = 195$); analyses comparing admission and discharge data were carried out on the treatment completer group ($n = 162$).

Prevalence of Loss of Dignity

The distribution of LoDi scores at admission is shown in Table 2. Almost half of the patients ($n = 96$; 49.2%) acknowledged no loss of dignity at all. Of the remainder, 74 individuals (37.9%) received scores indicating minimal or mild loss of dignity, which was below the threshold for a clinically significant problem. Twenty-five patients (12.8%) received moderate-to-extreme LoDi scores, indicating that they considered loss of dignity to be a significant ongoing concern. These individuals are considered to have had a fractured sense of dignity.

Correlations Between Loss of Dignity and Other Baseline Variables

Demographics. At baseline, bivariate correlations between scores on the LoDi and demographic characteristics revealed a significant negative correlation with age ($r = -.31$, $p < .01$; see Table 3).

Respiratory function and exercise performance. None of the measures of respiratory function or exercise performance was correlated significantly with the LoDi scores at baseline.

Psychological variables. At program admission, interviewer ratings on the LoDi were correlated with patient self-reports on the BCS ($r = .28, p < .001$), ASI ($r = .24, p < .01$), BDI-II ($r = .44, p < .001$), and PHQ-9 ($r = .37, p < .01$), but not with the CSES or SPBS.

Change In Loss Of Dignity With Pulmonary Rehabilitation

At discharge, there was a robust improvement in LoDi ratings among those patients who reported a fractured sense of dignity at admission. Of those 25 individuals, 22 (88%) received LoDi scores < 3 at discharge. Moreover, none of the patients who reported an intact sense of dignity at admission reported a fractured sense of dignity at discharge, McNemar's $\chi^2(1, n = 162) = 20.05, p < .001$.

The LoDi scores of patients who reported a fractured sense of dignity at admission were also compared with the rest of the sample using a 2 X 2 (Group X Time) repeated measures ANOVA. The scores are shown in Table 4 and Figure 1. In addition to the main effect of group, LoDi scores showed a significant main effect of time, $F(1, 160) = 168.33, p < .001, h_p^2 = .57$, indicating an overall decrease in loss of dignity following rehabilitation. The Group X Time interaction was also significant, $F(1, 160) = 82.30, p < .001, h_p^2 = .40$, with a large decrease in loss of dignity occurring in the high-scoring LoDi group. However, this group still had higher scores at discharge than the rest of the sample.

Comparisons of Patients With Or Without A Fractured Sense Of Dignity

Compared to individuals with an intact sense of dignity, those with a fractured sense of dignity were younger ($t(193) = 2.89, p < .01$) and more likely to be female ($p = .005$, Fisher's exact test). There was a 20.5% prevalence of fractured dignity among women (18 of 88), compared to a 6.5% prevalence among men (7 of 107).

The pre- and post-rehabilitation scores for measures of pulmonary, physical, and

psychological function are shown in Table 4. These data were analyzed in a series of 2 X 2 (Group X Time) repeated measures ANOVAs. With the exception of the FEV₁%, FVC% and SPBS ($ps > .10$) patients improved on all measures of pulmonary, physical and psychological function, $ps < .05$.

On the physical performance measures, there were significant improvements over time for the 6MWT, $F(1, 60) = 4.17, p = .046, h_p^2 = .07$, the NSWT, $F(1, 160) = 51.33, p < .001, h_p^2 = .26$, and stairs test, $F(1, 160) = 10.27, p = .002, h_p^2 = .07$, but no significant main effects of group, nor interactions, $ps > .05$.

As shown in Figure 1, there were significant group main effects for the ASI, $F(1, 160) = 3.97, p = .049, h_p^2 = .04$; and BDI-II, $F(1, 76) = 28.37, p < .001, h_p^2 = .40$. In both cases, participants with a fractured sense of dignity had higher scores at both admission and discharge. Significant main effects of time were demonstrated for the BCS, $F(1, 160) = 18.96, p < .001, h_p^2 = .11$; ASI, $F(1, 160) = 6.31, p = .002, h_p^2 = .04$; BDI-II, $F(1, 76) = 12.68, p = .003, h_p^2 = .10$; PHQ-9, $F(1, 82) = 22.80, p < .001, h_p^2 = .40$; and CSES, $F(1, 160) = 6.76, p = .012, h_p^2 = .06$. The SPBS did not demonstrate any significant main effects. Although no significant group main effect was demonstrated with the PHQ-9, a significant interaction was observed, $F(1, 82) = 4.16, p = .01, h_p^2 = .07$. Patients with a fractured sense of dignity had higher PHQ-9 scores at admission, but not at discharge.

Discussion

The first goal of this study was to examine the prevalence and correlates of loss of dignity among patients receiving pulmonary rehabilitation for Stage III or IV COPD. We found that about half of the respondents reported no loss of dignity, and another 38% reported only minimal

or mild concerns. Importantly, however, about 13% of patients reported a fractured sense of dignity that was a significant ongoing problem. Among patients with cancer who have been interviewed with the SISC LoDi, 5-10% have reported a similar level of concern (Chochinov et al., 2002; Chochinov et al., 2006; de Faye et al., 2006; Wilson, Chochinov, Skirko et al., 2007; Wilson et al., 2004). Hence, it appears that among patients with severe COPD, concerns about loss of dignity are at least as prevalent as among patients receiving palliative care for cancer.

The interviewer LoDi scores showed no significant correlations with spirometric measures or exercise performance. Thus, among patients with severe or very severe COPD, all of whom have compromised pulmonary capacity, loss of dignity is relatively uninfluenced by variations in medical or functional status. In contrast, significant correlations were demonstrated with measures of anxious and depressive symptoms, including the BCS, ASI, BDI-II, and PHQ-9. Chochinov et al. also reported a significant correlation with depression in the context of palliative cancer care, suggesting that loss of dignity may comprise part of the spectrum of distress among people with different medical illnesses. Nevertheless, there were some results that did not replicate previous findings. For example, loss of dignity was not associated with self-perceived burden, which Chochinov et al. (2002) found to be a unique and independent predictor of LoDi scores among patients receiving palliative care for cancer. This may be explained by the comparatively higher level of functioning of patients in the current study, who were limited in mobility but uniformly independent for such activities of daily living as toileting and personal care.

Loss of dignity was experienced most acutely by younger individuals, again replicating a finding by Chochinov et al. (2002). It has been suggested that higher levels of distress reported by younger patients with life-threatening illness may be due to less effective coping strategies for

diseases of aging; greater social, family and occupational disruption; a greater readiness to divulge psychological concerns; or a stronger sense that the diagnosis and its impact are untimely (Carlson et al., 2004; Chochinov et al., 2006; Thompson et al., 2009; Wilson et al., 2009; Wilson, Chochinov, McPherson et al., 2007; Wilson, Chochinov, Skirko et al., 2007). These considerations may also hold for the loss of dignity.

Unexpectedly, we also found that women were more likely than men to experience a fractured sense of dignity. Among those receiving palliative care for cancer, women more often identified changes in appearance and cognition as negatively impacting dignity (Chochinov et al., 2006). Although gender differences are not always evident in studies of patients with COPD, Laurin et al. (2007) reported that female patients tend to have a higher prevalence of psychiatric disorders, self-devaluing, and social disengagement. We did not have concurrent assessments of these issues in the present study, but it is possible that similar processes may explain why women with COPD would experience a greater loss of dignity than men.

The second goal of this study was to examine whether loss of dignity changes with treatment. The results indicated that it does indeed improve robustly; of 25 individuals who reported a fractured sense of dignity at admission, 22 (88%) scored below the LoDi clinical significance threshold at discharge. Importantly, none of those reporting an intact sense of dignity at admission were affected adversely in this regard. Overall then, loss of dignity is a psychological construct related to other measures of distress. It is experienced most acutely by younger patients, particularly women, but in the context of severe COPD, is relatively independent of lung function, performance status, or sense of being a burden to others. Loss of dignity is not a permanent state, however, and it is amenable to change. Moreover, patients with a fractured sense of dignity are likely to benefit from rehabilitation in much the same way as

individuals whose dignity is intact.

In a broader context, the finding that loss of dignity can be improved with appropriate treatment is relevant to ongoing discussions around “death with dignity.” As a growing number of jurisdictions have introduced legislation in support of medical decisions to end life, such as euthanasia and physician-assisted suicide, a common theme is the emphasis on the preservation of dignity. Indeed, among terminally ill patients who request medical aid in dying, loss of dignity is often cited as a prominent reason underlying their requests (Ganzini, Goy, & Dobscha, 2009; Loggers et al., 2013; Oregon Health Authority, 2014; van der Maas, van Delden, Pijnenborg, & Looman, 1991). Although there may come a point in the trajectory of a life-threatening illness when the perception of a loss of dignity is irreversible, the present findings indicate that clinically meaningful changes in a fractured sense of dignity can be achieved with appropriate rehabilitation, and, perhaps, palliative intervention.

There are a number of limitations in this study. Primary among these is that the pulmonary rehabilitation program was not designed with the explicit intention of addressing loss of dignity. Therefore, the specific factors that might mediate such change remain to be determined. Secondly, the outcome assessments of loss of dignity were not blinded, and the clinicians conducting the assessment interviews were part of the team involved in patient care. Finally, due to program considerations outside the scope of this research, the depression measure used was changed part way through the study period.

In summary, the present findings indicate that a fractured sense of dignity is at least as common among patients with Stage III or IV COPD as among patients receiving palliative cancer care. Therefore, loss of dignity is a broader concern among the medically ill generally, and is not necessarily limited to the end-of-life. Importantly, loss of dignity can be reduced with

appropriate interdisciplinary care, at least among those who are well enough to benefit from rehabilitation.

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Table 1
Baseline Demographic and Medical Characteristics of Participants

Characteristic	Total sample (N = 195)				Intact Sense of Dignity (n = 170)				Fractured Sense of Dignity (n = 25)			
	M	SD	N	%	M	SD	n	%	M	SD	n	%
Age (years)	64.6	11.2			65.5	10.6			59.8	13.1		
Female/male			88/107	45.1/54.9			70/100	41.1/58.9			18/7	71.4/28.6
FEV ₁ %	31.1	9.9			31.1	10.2			31.0	8.0		
FVC%	55.9	17.8			56.1	18.1			55.0	15.9		
BMI					27.5	8.4			29.3	10.0		
Prescription												
None			4	2.1			1	0.6			3	12.0
BD			183	93.8			160	94.1			23	92.0
Steroid			50	25.6			43	25.3			7	28.0
BDST			150	76.9			135	79.4			15	60.0
Oxygen			57	29.2			47	27.6			10	40.0

Note. FEV₁% = forced expiratory volume in one second, % predicted; FVC% = forced vital capacity, % predicted; BMI = body mass index; BD = bronchodilator; BDST = bronchodilator-steroid combination.

Table 2
Distribution of Loss of Dignity Item Scores (N = 195)

Score	Description	<i>n</i>	%	Grouping
0	No loss of dignity	96	49.2	Intact
1	<i>Minimal</i> —e.g., only occasionally feels some loss of dignity; not regarded as a particular problem	34	17.4	
2	<i>Mild</i> —e.g., sometimes experiences low-grade worry about loss of dignity; may occasionally (but infrequently) feel somewhat ashamed or degraded; occasionally regarded as a minor problem	40	20.5	
3	<i>Moderate</i> —e.g., definite concerns about loss of dignity; may often feel somewhat degraded, ashamed, or embarrassed; generally regarded as a significant problem	15	7.7	Fractured
4	<i>Strong</i> —e.g., most of the time feels a clear sense of loss of dignity; frequently feels degraded, ashamed, or embarrassed; regarded as a prominent and ongoing problem	6	3.1	
5	<i>Severe</i> —e.g., sense of loss of dignity is almost always present; very frequently feels degraded, ashamed or embarrassed; regarded as troubling, serious, and ongoing problem	3	1.5	
6	<i>Extreme</i> —e.g., sense of loss of dignity is virtually constant; almost always feels degraded, ashamed, or embarrassed; regarded as a pervasive, consuming, and constant problem	1	0.5	

Table 3

Correlations Between Measures at Baseline

	BCS	ASI	BDI-II ^a	PHQ-9 ^a	CSES	SPBS	FEV ₁ %	FVC%	6MWT ^a	NSWT	Stairs	Age
LoDi	.28**	.24*	.44**	.37*	.13	.08	-.04	.00	.11	-.08	-.09	-.31*

Note. *N* = 195. LoDi = Loss of Dignity item; BCS = Breathlessness Catastrophizing Scale;

ASI = Anxiety Sensitivity Index; BDI-II = Beck Depression Inventory-II; PHQ-9 = 9-Item Patient Health Questionnaire;

CSES = COPD Self-Efficacy Scale; SPBS = Self-Perceived Burden Scale;

FEV₁% = forced expiratory volume in one second, % predicted; FVC% = forced vital capacity, % predicted;

6MWT = Six-Minute Walk Test; NSWT = Non-Stop Walk Test.

^aDue to program and clinical considerations not all patients completed all measures included here: BDI-II (*n* = 106);

PHQ-9 (*n* = 89); 6MWT (*n* = 66).

p* < .01, two-tailed. *p* < .001, two-tailed

Table 4

Change in Outcome Measures from Admission to Discharge

Variable	Intact Sense of Dignity ($n = 137$) ^b				Fractured Sense of Dignity ($n = 25$) ^b			
	Admission		Discharge		Admission		Discharge	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
FEV ₁ %	31.1	10.2	32.8	12.2	31.0	8.0	30.1	10.5
FVC%	56.1	18.1	59.6	16.5	55.0	15.9	50.6	17.4
6MWT, m ^a	305.0	85.8	331.4	84.0	317.0	52.6	325.0	106.4
NSWT, m	452.8	360.7	679.8	268.7	439.8	335.7	675.4	277.6
Stairs, steps	20.9	14.2	26.8	19.6	20.3	14.9	23.9	14.6
BCS	17.8	11.4	12.2	11.1	25.3	12.5	16.2	10.2
ASI	20.2	10.4	16.5	12.8	26.2	11.7	23.4	9.8
BDI-II ^a	10.7	7.2	5.5	4.4	21.3	8.2	17.6	5.0
PHQ-9 ^a	5.0	4.0	3.2	4.1	10.3	7.7	4.9	6.0
CSES	106.2	14.7	82.6	28.2	111.1	9.8	98.7	30.5
SPBS	21.7	9.4	21.2	8.4	24.3	8.9	25.3	8.3
LoDi	0.6	0.8	0.2	0.4	3.7	0.9	1.2	1.2

Note. FEV₁ = forced expiratory volume in one second, % predicted;

FVC = forced vital capacity, % predicted; 6MWT = Six-Minute Walk Test;

NSWT = Non-Stop Walk Test; BCS = Breathlessness Catastrophizing Scale;

ASI = Anxiety Sensitivity Index; BDI-II = Beck Depression Inventory-II;

PHQ-9 = 9-Item Patient Health Questionnaire; CSES = COPD Self-Efficacy Scale;

SPBS = Self-Perceived Burden Scale; LoDi = Loss of Dignity item.

^aDue to clinical and program considerations not all patients completed all measures included here: 6MWT ($n = 62$); BDI-II ($n = 78$); PHQ-9 ($n = 84$).

^bAll measures demonstrated significant improvement from admission to discharge ($ps < .05$), with the exception of FEV₁%, FVC%, and SPBS.

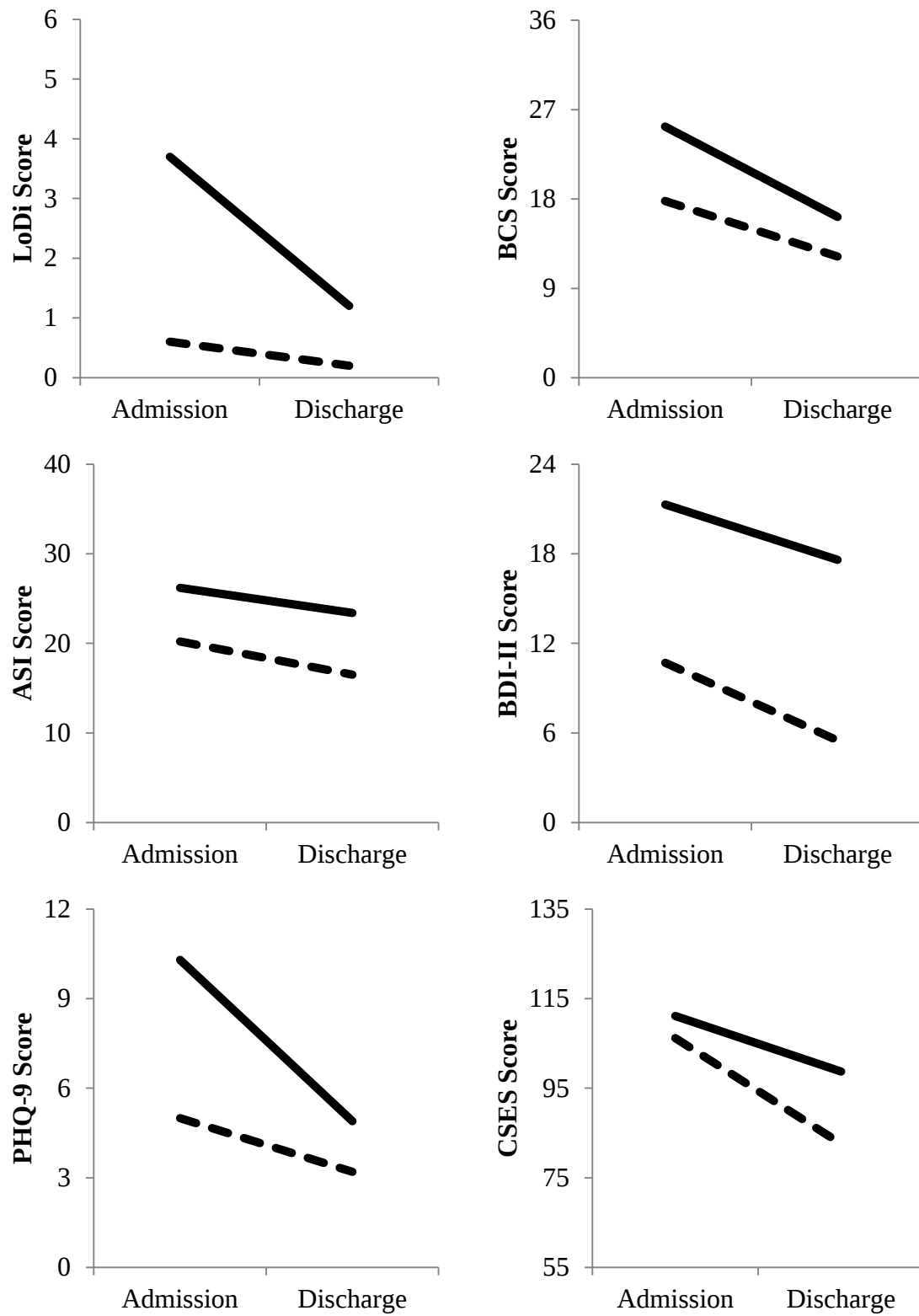
*Figure 1.*

Figure 1. Admission and discharge scores by time and LoDi group. The y-axis of the LoDi graph represents the range of possible LoDi scores. The y-axes of the other graphs are centered around the grand mean ± 2 SD. Solid lines represent those reporting a fractured sense of dignity; dashed lines represent the rest of the sample. (LoDi = Loss of dignity item from the Structured Interview for Symptoms and Concerns, BCS = Breathlessness Catastrophizing Scale, ASI = Anxiety Sensitivity Index, BDI-II = Beck Depression Inventory-II, PHQ-9 = 9-Item Patient Health Questionnaire, CSES = COPD Self-Efficacy Scale; LoDi, BCS, ASI, CSES: $n = 186$; BDI-II: $n = 78$; PHQ-9: $n = 84$.)

Chapter 4

- Discussion -

Discussion

As a disease that is a leading cause of both disability and death, COPD falls within the purview of both rehabilitation and palliative care. Unlike some other illnesses, the uncertain trajectory of COPD results in an indistinct boundary between chronic and terminal illness. As such, those with COPD represent a population with concurrent rehabilitative and palliative needs.

One theme of this dissertation is to examine psychological constructs that are drawn, in part, from rehabilitation, and in part, from palliative care. Study 1 draws on the rehabilitation literature and focuses on catastrophizing as an issue related to functional disability. Study 2 draws on the palliative care literature and examines the loss of dignity among those facing the greatest likelihood of life-threatening exacerbations.

Catastrophizing

Our interest in catastrophizing was grounded in certain parallels between the experience of COPD and that of individuals with other chronic medical conditions, particularly chronic pain. For example, breathlessness is a prominent primary symptom for people with COPD, and may be analogous in this context to the problem of pain in people with chronic pain conditions. Both symptoms vary in intensity, but they can be provoked by activity to the point of overwhelming disability. Moreover, dyspnea is known to be correlated with dimensions of psychological distress, such as anxiety and depression, as is pain intensity in people with chronic pain. Indeed, in the case of chronic pain, catastrophizing has sometimes demonstrated an even stronger relationship with disability than has pain intensity (Crombez et al., 1999). As a result, Vlaeyen and Linton (2000) developed the fear-avoidance model relating hypervigilance to, fear of, and catastrophizing about pain, to activity avoidance and progressively worsening disability. If

comparable processes are relevant in COPD, it could be hypothesized that patients who catastrophize about dyspnea would demonstrate diminished functional performance and reduced benefit from rehabilitation.

In fact, the evidence supporting this hypothesis was limited. In the correlational analyses of the baseline data, no significant relationship was demonstrated between catastrophizing and walking and stair-climbing tests of functional performance. Moreover, even patients who demonstrated a high level of catastrophizing about dyspnea at admission were able to achieve significant functional gains. Although the high catastrophizing group tended to show less improvement on the stairs test, the effect size was small. It appears, therefore, that catastrophizing may not raise the same barriers to functional performance among those with dyspnea as it does among people with chronic pain.

One consideration in explaining this discrepancy is that study participants were inpatients in an intensive pulmonary rehabilitation program that offered multiple participation-promoting features. These included: (1) a schedule and structure that mitigated against the avoidance of activities appraised as threatening; (2) an interdisciplinary approach that provided multiple avenues of treatment engagement; (3) an environment with specialized equipment, expertise, and emergency support services that effectively eliminated the risk of harm when engaging in difficult activities; and (4) a culture that fostered engagement.

In many regards the pulmonary rehabilitation program offers an excellent opportunity for psychosocial research. The environment is well controlled, there is a systematic approach to assessment, and the treatment protocol follows the standards of care established by GOLD and the WHO. It should be noted, however, that patients' performance in this type of supervised setting may not be representative of their behaviour in daily life. Future studies of

catastrophizing could build on the present work by examining level of patient engagement in the process of rehabilitation, or by expanding into more naturalistic designs. These could include investigations of diary-based or ambulatory monitoring of activity levels in the community, and patient decision making about when to seek medical or emergency care.

Alternatively, it is also possible that catastrophizing about dyspnea is less relevant to patients with COPD than pain catastrophizing is to patients with chronic pain. That is, the differences between the two medical problems may be more important than the similarities. The apparent contrast in the factor structures of the BCS and PCS supports this possibility. It may be, for example, that while pain conditions allow for the consistent avoidance of environmental triggers, or the use of effective self-care strategies (e.g., pacing, planning, relaxation), the acute exacerbations and progressive deterioration of even well-managed COPD may be ultimately unavoidable. In this event, avoidance of physical activities may be a less effective strategy for COPD patients who are attempting to limit their experience of severe breathlessness.

This hypothesis may be testable in future research. COPD patients are largely older adults, and as such may have medical comorbidities caused by other diseases of aging. Some of these problems, such as osteoarthritis of the joints, cause chronic pain. Thus, it should be possible to examine the functional associations of both pain catastrophizing and breathlessness catastrophizing, concurrently in the same cohort of patients, by recruiting participants with COPD who also have chronic arthritic pain. This type of research could help to elucidate whether catastrophizing has trait as well as state characteristics, and offer a greater understanding of the construct as a whole.

Loss of Dignity

The palliative care literature provided the basis for examining the loss of dignity in patients with COPD. Again, the key findings were: (1) loss of dignity is at least as prevalent among patients with COPD as among those with advanced cancer; (2) loss of dignity is correlated with other measures of psychological distress, but not with pulmonary function or behavioural measures of performance status (recognizing that all participants had important deficits in these areas); (3) younger patients, and particularly women, are most at risk for experiencing loss of dignity; and (4) loss of dignity improves with participation in rehabilitation.

Although the improvement in patient dignity was robust, it must be acknowledged that the pulmonary rehabilitation program was not designed specifically with the intention of alleviating fractured dignity. As such, the mediating mechanisms that may be responsible for the observed change are not readily identifiable. However, Chochinov's Model of Dignity in the Terminally Ill (Chochinov et al., 2002; see *Figure 1*, page 39) offers a conceptual framework for considering the processes that may be involved.

Chochinov et al. (2002) conducted semi-structured interviews with terminally ill cancer patients in order to examine how the symptoms and circumstances imposed by their advanced disease affected their view of personal dignity. Qualitative analyses were used to identify the factors that were most influential in maintaining or diminishing the sense of dignity. As shown in *Figure 1* (see page 39), these factors were categorized into the three major dimensions of Illness Related Concerns, Dignity Conserving Repertoire, and Social Dignity Inventory, each with embedded sub-themes.

Illness Related Concerns refer primarily to the medical symptoms and functional consequences of the underlying disease. In the present context, these concerns are also those that

comprise the primary focus of the pulmonary rehabilitation program. For example, the level of independence is addressed through physiotherapy and the promotion of physical fitness, and symptom distress is targeted throughout the program by medical and psychosocial intervention by various members of the interdisciplinary team.

The Dignity Conserving Repertoire is largely a cognitive and behavioural dimension. It is composed of perspectives on one's self, as well as attitudes and beliefs about one's situation that can conserve or erode the sense of dignity. In addition, there are actions or habits that one can undertake that may either protect or threaten dignity. The psychological and social components of the pulmonary rehabilitation program may address sub-themes such as continuity of self, role preservation, hopefulness, control, acceptance, and resilience, under the purview of individual and group based interventions. Additionally, social work and psychology may play a role in helping the patient to maintain or re-establish autonomy, a sense of normalcy, or to seek spiritual comfort.

The Social Dignity Inventory encompasses interpersonal concerns or dynamics that are most salient to the patient's dignity. These include the patient's altruistic concerns about the welfare of others, the desire not to burden others, and aftermath concerns about how loved ones will manage after the patient's eventual death. Other aspects of the Social Dignity Inventory pertain to the interaction of the individual with broader social systems, including the health care system. These sub-themes encompass such issues as the preservation of privacy and the care tenor with which one is treated by health professionals.

It is possible that the themes of this category were addressed sufficiently by the pulmonary rehabilitation program. With adequate interdisciplinary care, an affirming interpersonal manner by the treating staff, and recognition and respect of privacy boundaries the

program may have provided a social milieu that bolstered patient dignity. In addition, the group dynamic of some interventions may have fostered a greater sense of social support through normalization, peer interaction, and the realization that one is not alone in the experience of COPD.

The last two themes of the Social Dignity Inventory, aftermath concerns and burden to others, may not be especially prominent in this population. As individuals engaged in a rehabilitation program, these patients were likely not preoccupied with the impact their death would have on others; their focus is on improving their quality of life rather than preparing for death. Moreover, their generally high level of independence for personal care may have rendered irrelevant any sense of self-perceived burden to others as a factor that impacted dignity.

Recognizing that this interpretation cannot be definitive, it elucidates the ways in which the pulmonary rehabilitation program may have addressed the dignity-related concerns of the study participants.

Limitations

Sample Size.

The dissertation studies were based on a relatively large clinical cohort of patients participating in a pulmonary rehabilitation program, with data collected by professionals from different health care disciplines. This involved the recruitment of patients who were admitted consecutively over a period of five years. Although this required considerable commitment by all involved, the final studies are still limited with respect to sample size. This is a particular issue for the study of loss of dignity, which (a) investigated a problem that affected only 13% of participants, and (b) was restricted to the subset of patients with severe or very severe COPD. Comparisons of patients with or without a fractured sense of dignity would therefore reveal only

relatively powerful effects. Moreover, the sample size would not support further subgrouping of those 25 individuals who had a fractured sense of dignity at admission.

This is an unfortunate limitation given the interesting questions that arose concerning gender and loss of dignity. Although we were able to demonstrate that women with severe COPD experience greater loss of dignity than men, the sample size was too small to support gender-based comparisons that might help to explain it further. Hopefully, future studies will benefit from the prevalence estimate established in this research, in order to address this question. Clearly, however, these studies will have to be very large.

Chart Review.

The data collection for these studies was based on reviews of hospital charts. According to Vassar and Holzmann (2013), the ten key considerations for chart review methodology are: (1) articulated guiding research questions, (2) a priori review of sampling questions, (3) operationalized variables, (4) training and monitoring of data collectors, (5) uniform data collection forms, (6) data collection procedures, (7) explicit inclusion and exclusion criteria, (8) assessment of inter- and intra-rater reliability, (9) pilot test of data collection, and (10) confidentiality and ethical protocols. All of these considerations were observed, with the exception of the assessment of inter- and intra-rater reliability. Discipline-specific clinicians collected raw data in the context of clinical care, and repeated assessment of particular patients by these, or alternate, clinicians was not provided. Therefore, this undetermined aspect of reliability represents a limitation of these studies.

The BDI-II and PHQ-9.

During the period for which data were collected, the pulmonary rehabilitation program changed its assessment of depression from the BDI-II to the PHQ-9. This was done because the

BDI-II is a proprietary measure that must be purchased by the program (at over \$3 per administration), whereas the PHQ-9 is in the public domain. Both measures are widely accepted for research and clinical purposes, but in the present studies they sometimes led to different results. In Study 1, where groupings were based on BCS score, the PHQ-9 demonstrated a main effect of group, while the BDI-II demonstrated a Group X Time interaction. In Study 2, where groupings were based on LoDi score, these effects were reversed.

Only a few studies have compared the two measures directly. When administered to the same patients, BDI-II and PHQ-9 scores generally correlate in the range of $r = .67$ to $.77$ (Kung, Alarcón, Williams, Poppe, Moore, & Frye, 2013), which is high enough for some authors to consider them interchangeable. Nevertheless, there are differences. For example, Titov et al. (2011) performed a psychometric comparison of the BDI-II and PHQ-9. They found that the BDI-II categorized a greater proportion of participants with more severe depression and that the PHQ-9 more often demonstrated that criteria for clinically significant change had been met.

Factor structure appears to be another potential point of contrast between the BDI-II and PHQ-9. The 21 items of the BDI-II are thought to encompass two factorially distinct but correlated subscales reflecting somatic-affective (12 items) and cognitive (9 items) dimensions (Beck et al., 1996). Although the factor structure may vary to some extent across different populations, the distinction between somatic and cognitive elements is generally robust (Dum, Pickren, Sobell, & Sobell, 2008; Kneipp, Kairalla, Stacciarini, & Pereira, 2009; Manian, Schmidt, Bornstein, & Martinez, 2013; Vanheule, Desmet, Groenvynck, Rosseel, & Fontaine, 2008). The PHQ-9, on the other hand, has been less consistent in this regard, and there is compelling evidence to support both one-factor (Dum et al., 2008; Ryan, Bailey, Fearon, & King, 2013; Xiong et al., 2015) and two-factor models (Chilcot et al., 2013; Elhai et al., 2012;

Petersen, Paulitsch, Hartig, Mergenthal, Gerlach, & Gensichen, 2015; Richardson & Richards, 2008). For example, the PHQ-9 has sometimes demonstrated a factor structure that has no separate cognitive element (Richardson & Richards, 2008). This distinction between the BDI-II and PHQ-9 may highlight a differential emphasis on cognition as a key component in depressive symptomatology.

The possible differences in factor structure between the BDI-II and the PHQ-9 have yet to be explored among patients with COPD, and are beyond the scope of the present dissertation. Evidently, the two measures respond in subtly different ways in this population, for reasons that are not entirely clear. The two measures address overlapping, but not identical, symptoms of depression, using different response formats. Although both are correlated with breathlessness catastrophizing and loss of dignity, they are not interchangeable.

The 6MWT and NSWT.

Although the 6MWT is a standard measure of functional capacity in rehabilitation studies, medical contraindications limited its applicability to only 40% of patients in the present research ($n = 98$). Therefore, the physiotherapists with the pulmonary rehabilitation program also use the NSWT as an alternative measure. The NSWT is in line with the recommendation of the developers of the 6MWT that longer walking intervals are preferable, where feasible. It should be noted, however, that the NSWT is not a validated measure. It would be valuable for a future study to either validate the NSWT in comparison with the 6MWT, or to develop a comparable measure. The present research found that the 6MWT and NSWT were correlated substantially ($r = .74$), but not perfectly.

Non-completers.

Finally, it is important to note that the patients who did not complete the pulmonary rehabilitation program were excluded from the comparative analyses, which may bring a bias to the findings. Patients included in the analyses did demonstrate improvements in a majority of the outcome measures, but their experience may not reflect that of those who did not complete the program. Patients left treatment for a variety of reasons, which, unfortunately, were not always documented in the clinical record. Some, however, could not continue because of medical illness that required acute hospitalization or interruption of rehabilitation. In these cases, it is possible that the benefits of rehabilitation would have been diminished, had the patients continued. Other individuals may have dropped out of the program because of the perception of insufficient improvement. In this event, their exclusion from the analyses would introduce a bias in favour of documenting positive outcomes.

Statistical methods for handling patient attrition represent a significant concern for clinical research. One approach that is sometimes recommended is the “intention-to-treat” analysis (ITT). The goal of ITT is to retain the data of non-completers to ensure that they are represented throughout study analyses, arguably giving a more accurate depiction of treatment outcomes. One such approach is to impute non-completers’ admission scores as their discharge scores. This offers a conservative estimate of their outcomes, presuming neither improvement nor decline over the course of treatment. Ultimately, an ITT approach was not attempted in this research, however, because of the reciprocal risk of minimizing or masking the benefits achieved by some individuals. Instead, non-completers were acknowledged in the sample descriptions and compared with completers based on the measures administered at admission. Further, the potential bias in the findings is being explicitly addressed here in an effort to ensure it is not

overlooked. Nevertheless, it must be acknowledged that non-completers may have had quite a different experience of the benefits of pulmonary rehabilitation, and that experience is not reflected in the analyses as conducted.

A Synthesis of Rehabilitation and Palliative Care for COPD

Each of these studies builds on the base of knowledge of their own frame of reference within either the rehabilitation or palliative care literatures, but neither represents the full picture. This dissertation offers an opportunity to consider whether a pulmonary rehabilitation program, such as the one examined here, can serve as a workable model for a synthesis of these two perspectives.

The individual's experience.

Many individuals with COPD will gradually give up physical activities or begin avoiding activities of daily living as a means of coping with their symptoms (Arne, Emtner, Janson, & Wilde-Larsson, 2007; Chan, 2004; Habraken, Pols, Bindels, & Willems, 2008). However, the experience of those with COPD is not only one of progressive decline in function and quality of life, but also one characterized by stark shifts (GOLD, 2013). An emergency exacerbation leads to the first presentation for many who will receive a diagnosis (Bastin et al., 2010). Despite what may be recognized later as a history of symptoms, the patient's formal introduction to the disease will often follow an acute episode of severe symptomatology (Bastin et al., 2010). Among those who may perceive gradually increasing shortness of breath, feelings of shame and stigma around having a disease that may be self-inflicted by tobacco smoking can impede their engagement in self-management (Sheridan et al., 2011), or delay their seeking of medical aid, or acting on such aid, once offered (Arne et al., 2007).

Importantly, however, it is not disability alone that those with COPD face. For those with advanced disease, the possibility of a terminal prognosis represents a threat to survival itself (Lindgren, Storli, & Wiklund-Gustin, 2014). When the diagnosis is made, the patient often contends with a profound sense of loss (Oliver, 2001). As medical interventions offer little more than symptom management, patients can also be overwhelmed with the sense that little can be done, perhaps leading to hopelessness (Oliver, 2001). Just as shame can influence how a patient manages disability, it can also play a role in adjustment to a life-threatening diagnosis. Self-blame can result in greater shame (Sheridan et al., 2011) and even a fundamental questioning of sense of dignity and self (Lindgren et al., 2014).

An integrated model of care.

While there is certainly utility in isolating specific constructs such as catastrophizing and loss of dignity in the context of focused research, when it comes to patient care it must be acknowledged that the patient's experience exists as a whole. It is for this reason that there has been a call for a model of treatment that integrates rehabilitation and palliative care in COPD (American Thoracic Society End-of-Life Care Task Force [ATS Task Force], 2008; Bausewein et al., 2010; Higginson et al., 2014). Yet, despite the demonstrated benefits to symptom management and quality of life that can arise from this blended model (Bakitas et al., 2009; Higginson et al., 2014; Higginson et al., 2009; Temel et al., 2010; Zimmerman et al., 2014), implementation of a conjoint approach is rare and has yet to represent the standard of care (Higginson et al., 2014).

An integrated model includes both curative treatment focused on modifying underlying disease or improving physical functioning and supportive care aimed at relieving suffering or improving quality of life (Health and Welfare Canada, 1987; see *Figure 2*, page 40, as adapted

by CHPCA, 2002). In contrast to the more traditional serial implementation, concurrent implementation of these interventions allows patient palliative needs to be addressed at any point following initial diagnosis (Bausewein et al., 2010; Higginson et al., 2014), while allowing for greater individualization of care at any point along the disease trajectory (ATS Task Force, 2008; CHPCA, 2002).

Clinical culture as a barrier to integration.

One possible explanation for the failure to employ an integrated model is that a cultural divide exists between the communities of clinicians practicing rehabilitation and those practicing palliative care. Difficulties can arise right at the point of COPD diagnosis, which is not always communicated clearly (Arne et al., 2007; Giacomini, 2012; Walters, Hansen, Walters, & Wood-Baker, 2008). In particular, information about prognosis and future management is not always forthcoming (Gore et al., 2000). In fact, Walters et al. (2008) noted that some clinicians intentionally avoid giving an early diagnosis, partly because they believe that the patient may not be prepared to hear it, and partly because of their own discomfort with the prognosis.

The finding in Study 2 that 13% of rehabilitation patients with severe COPD demonstrated fractured dignity at admission may offer an opportunity to bridge part of the cultural divide. In contrast to previous studies of fractured dignity among patients receiving palliative cancer care, the participants in Study 2 were not clearly at the end of life. This suggests that fractured dignity can be a concern among a broader range of medically ill populations, and is not solely a concern that emerges in the final weeks of life.

Emphasizing such commonalities can facilitate greater collaboration among clinicians of both communities. For patients with severe COPD, preparing for exacerbations that may be life-threatening is a reasonable treatment goal, even while pursuing concurrent rehabilitation. Areas

of comparability with palliative cancer allow an identified need to be addressed without detracting from ongoing rehabilitative interventions. As such, palliative care can be introduced as a resource, instead of a competing interest.

Communication.

Diagnoses and prognoses are often rendered by the assessing specialist or referring clinician, neither of whom is likely to have expertise in recognizing or working with the existential distress that can arise over the course of illness. Integration of palliative care into the traditional biopsychosocial model can offer an advantage in this regard, particularly with respect to encouraging communication.

When it becomes apparent medically that a patient's lung function has declined to the extent that an acute exacerbation may prove fatal, it can be important to begin the discussion around advance care planning. Palliative care offers special expertise in such planning, including directives, living wills, and options for end-of-life care. In some cases, communication tools have been developed to better identify, document, and implement the preferences of the patient.

For example, Wilson et al. (2005) developed a decision aid to help patients with COPD make advance decisions about mechanical ventilation in the event of a life-threatening exacerbation. The decision aid provides the patient with an audio-booklet that he or she can use at home, at a self-selected pace, and includes information about the: (1) etiology and symptomatology of COPD; (2) impact and prognosis of a life-threatening exacerbation; (3) procedures involved in mechanical ventilation, along with associated risks and benefits; and (4) alternative option of supportive end-of-life care focused on providing comfort as the patient dies of the respiratory crisis. Review of the audio-booklet is followed by a worksheet to help the patient engage in considerations of: (1) personal values; (2) preferred decision participation

roles; (3) questions about options around mechanical ventilation and supportive care; and (4) inclination toward choosing or refusing mechanical ventilation in the event of a life-threatening exacerbation. Among the patients who completed the decision aid (Wilson et al., 2005), over 90% were able to make an informed advance choice. Moreover, about two-thirds reported that the decision aid had acted as a catalyst for discussions about end-of-life planning with family members or health professionals.

Individuals with life threatening illnesses report that such discussions around planning for predictable life-threatening emergencies, and end-of-life care more broadly, are important for improving care (Heyland et al., 2010; Heyland et al., 2006). However, these discussions are rare in the course of hospital-based treatment (Heyland et al., 2013). To this end, Heyland, Tranmer, and Feldman-Stewart (2000) developed a communication framework designed to prompt discussions around end-of-life considerations. The two key components include: (1) education regarding prognosis, treatment options, and likely outcomes; and (2) discussion of considerations involved in order to render necessary decisions. This framework has been adapted by the Canadian Researchers at the End of Life Network (CARENET, 2014), which also emphasizes the patient's values as a central determinant in establishing the goals of care. CARENET's aim is to help clinicians gain greater confidence in their own abilities to engage in end-of-life conversations.

Rocker et al. (2015) go further in recognizing that such conversations, while often initiated for the benefit of identifying the patient's goals of care, foster a necessary dynamic of collaboration among patients, caregivers, and clinicians.

As such conversations develop over time, the emphasis can shift away from a specific focus on rendering a final code status to an ongoing process of communication (Simpson, 2012)

that is sensitive to the patient's decisional readiness as influenced by the needs and values that inform his or her preferences in care.

The benefits of such conversations could also extend to colleagues within the circle of care. Rocker et al. (2015) argue that insights gained during advance care planning should be shared so as to align the overall goals of care with the expressed needs of the patient. Communication of this kind could facilitate more regular engagement among the clinicians involved, leading to greater coordination of responsibilities and care that is more proactive.

Philosophy of care.

A final bridge in the cultural divide between clinicians providing rehabilitation and those providing palliation, may be realizing that their core principles of care need not be in conflict at all. The underlying precepts of emphasizing symptom management in combination with psychosocial and spiritual care are common to rehabilitative and palliative efforts (Chasen, Bhargana, & MacDonald, 2014). Johnson and Fallon (2013) argue that not only are these approaches vital to medical care at large, but that they warrant being underscored across disciplines. Some have called for the introduction of palliative care at initial diagnosis precisely so that it can be integrated into standard practice (American Society of Clinical Oncology [ASCO], 2012; Chasen et al., 2014).

Nevertheless, it is also important to note that palliative care has built a silo of its own. Over time, palliative services have developed expertise in physical, psychological, social, and existential considerations surrounding death and dying. In practice, however, most programs emphasize the care of individuals in the very end stages of disease (Chasen et al., 2014). Perhaps as a result of this, a misconception has arisen that sees palliative care as synonymous with the

end of life (ASCO, 2012). A move toward greater integration of palliative with primary care may help it to advance its breadth of expertise and contribution.

The American Society of Clinical Oncology (2012) proposes that an integrated model should emphasize medically appropriate goal setting, honest and open communication, and symptom management and control. Rocker et al. (2015) propose that as we move from a fragmented model to an integrated one, care will come closer to a holistic, individual-centred approach. We will not only be able to address the needs of individuals as they stand in the moment, but will be better prepared to move forward with them as they decline toward the end of life.

Conclusion

The two studies of this dissertation stem from approaches to care that are often regarded as distinct, if not divergent. For many individuals with chronic or terminal illnesses, either rehabilitation or palliation may prove sufficient. For those with COPD, however, both needs can coincide. As such, they are in a position to highlight the points of convergence between these two approaches; the pulmonary rehabilitation program offers an example of how such collaboration can work. It is hoped that just as the biomedical model expanded to accommodate psychosocial considerations, interdisciplinary care can come to see rehabilitation and palliative care as complementary modalities within a common framework.

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Appendix A

- Pulmonary Rehabilitation Program Description -

Pulmonary Rehabilitation Program at The Ottawa Hospital Rehabilitation Centre

The Pulmonary Rehabilitation Program at The Ottawa Hospital Rehabilitation Centre serves patients with chronic lung disease. The goals of the program are to help patients:

1. optimize their quality of life
2. reduce the intensity and fear of dyspnea
3. restore the highest possible level of functioning and sense of well-being

These goals are primarily addressed through:

1. increasing activity level via exercise training
2. reducing and managing symptoms, primarily dyspnea
3. education regarding all aspects of chronic lung disease
4. improving psychosocial and emotional well-being
5. fostering independence in self-management and activities of daily living

Program activities are categorized into three overlapping domains, as follows:

1. Endurance
 - a. Endurance: walking; treadmill; stationary cycling; walker evaluation
 - b. Strength: light weight training for arms and legs
2. Disease Symptom and Disability Management
 - a. Pacing: stairs; walking; daily functional activities
 - b. Lung secretion clearance: effective coughing; trial of techniques to loosen secretions, such as steaming, trunk flexibility exercises, flutter valve
 - c. Breath control: technique to improve pattern of breathing, shortness of breath, flutter valve
3. Education
 - a. Education: lung anatomy and physiology; pathophysiology of lung disease; lung hygiene management; medical management; medications; oxygen assessment; diet; energy conservation and work simplification; disease symptom and disability management; family sessions and family conferences; breathing training strategies; anxiety, symptom and self-management skill training

Though there is collaboration in service provision, some of the unique activities provided by each discipline are:

- Dietetics: admission assessment, 5 group education sessions
- Medicine: ongoing
- Nursing: weekly group education session
- Occupational Therapy: admission assessment, 4 group education sessions, discharge interview
- Pharmacy: ongoing
- Physiotherapy: admission assessment; 2x/day, except Wednesday morning, due to Inpatient Management Meeting; 8 topics covered in group education sessions; discharge assessment
- Psychology: admission assessment, 5 group education sessions, discharge assessment
- Recreation: weekly
- Respiratory Therapy: admission assessment, ongoing assessment, 6 group education sessions, discharge assessment

- Social Work: admission assessment, weekly group education session, post-weekend interviews
- Vocational Rehabilitation: as needed

The domain of education plays a prominent role in the content of the program. The following is a brief detailing of the group topics covered, by discipline.

Education Sessions

- Dietetics: 5 sessions
 - (1) Basic Nutrition Needs, (2) Weight Management, (3) Nutritional Challenges, (4) Food Fads (Fallacies), (5) Too much salt in my diet
- Occupational Therapy: 4 sessions
 - (1) Energy Conservation, (2) Pacing, (3) Planning, (4) Coping Techniques – The Six P's
- Respiratory Therapy: 6 sessions
 - (1) COPD: Oxygen, Blood Gases, and Spirometry, (2) COPD: Oxygen, Blood Gases, and Spirometry, continued, (3) Breathing Easier – Guide for Asthma and COPD, (4) Mayo Clinic COPD Patient Education, (5) Asthma Education, (6) Asthma Diary Form
- Physiotherapy: 8 topics
 - (1) Patient Knowledge Questionnaire, (2) Anatomy of Respiratory System, (3) COPD Disease Management, (4) Acapella, (5) Flutter, (6) Thoracic Mobility Exercise, (7) Home Exercise Program, (8) Bronchiectasis, Pulmonary Fibrosis, Pulmonary Hypertension
- Psychology: 5 sessions
 - (1) Acute versus Chronic Illness, (2) Anxiety Management, (3) Pacing, (4) Changing Lifestyle, (5) Loss and Grieving
 - Relaxation Techniques (5 strategies): (1) Things to Remember, (2) Daily Relaxation Script, (3) Relaxed Breathing – What do I do when I am out of breath?, (4) Body Scan, (5) Daily Relaxation Log

Appendix B

- Certificates of Ethical Approval -



Ottawa Hospital Research Ethics Boards / Conseils d'éthique en recherches

725 Parkdale Avenue, Box 411, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311
<http://www.ohrl.ca/ohreb>

December 10, 2010

Dr. Patricia Poulin
 The Ottawa Hospital Rehabilitation Centre
 505 Smyth Road
 Ottawa, ON
 K1H 8M2

Dear Dr. Poulin:

Re: Protocol # 2010900-01H A Fear-Avoidance Component to Disability in Chronic Obstructive Pulmonary Disease

Protocol approval valid until - December 9, 2011

Thank you for the email dated December 10, 2010. I am pleased to inform you that this protocol underwent expedited review by the Ottawa Hospital Research Ethics Board (OHREB) and is approved. No changes, amendments or addenda may be made to the protocol or the consent form without the OHREB's review and approval.

Approval is for the following:
 - COREB Application

The validation date should be indicated on the bottom of all consent forms and information sheets (see copy attached). If the study is to continue beyond the expiry date noted above, a Renewal Form should be submitted to the OHREB approximately six weeks prior to the current expiry date. If the study has been completed by this date, a Termination Report should be submitted.

We do, however, require the following information:

Provide a copy of TCPS Certification to OHREB

The Ottawa Hospital Research Ethics Board is constituted in accordance with, and operates in compliance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; Health Canada Good Clinical Practice: Consolidated Guideline; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Health Information Protection Act 2004 and its applicable Regulations.

Yours sincerely,

Raphaël Saginur, M.D.
 Chairman
 Ottawa Hospital Research Ethics Board

RS/ll



Ottawa Hospital Research Ethics Boards / Conseils d'éthique en recherches

725 Parkdale Avenue, Box 411, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311
<http://www.ohri.ca/ohreb>

December 25, 2012

Dr. Keith Wilson
The Ottawa Hospital Rehabilitation Centre - General Campus
Physical Medicine & Rehabilitation
Room 2405E, 505 Smyth Road
Ottawa, ON
K1H 8M2

Dear Dr. Wilson:

Re: Protocol # 2010900-01H A Fear-Avoidance Component to Disability in Chronic Obstructive Pulmonary Disease

Thank you for the Protocol Amendment Report dated October 10, 2012. The amendment is approved.

Approval of this amendment includes the following:

- Revised COREB application
- Data Collection Form (includes Assessment, National Rehabilitation Reporting System, Functional Independence Measure, and CIHI Cognitive Assessment), received October 11, 2012

We acknowledge the removal of Dr. Alikhan as Co-Investigator.

Ethical approval remains in effect until September 4, 2013.

Yours sincerely,

Raphaël Sagmou, M.D.
Chairman
Ottawa Hospital Research Ethics Board

RS/ll



Ottawa Hospital
Research Institute
Institut de recherche
de l'Hôpital d'Ottawa



uOttawa



UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

**Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du
Réseau de science de la santé d'Ottawa**

Civic Box 411 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax : 613-761-4311
<http://www.ohri.ca/ohsn-reb>

Tuesday, August 05, 2014

Dr. Keith Wilson
The Ottawa Hospital Rehabilitation Centre - General Campus
Physical Medicine & Rehabilitation
Room 2405E, 505 Smyth Road
Ottawa, ON
K1H 8M2

Dear Dr. Wilson:

**RE: Protocol# - 2010900-01H A Fear-Avoidance Component to Disability in Chronic Obstructive
Pulmonary Disease**

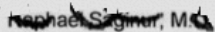
Renewal Expiry Date - Friday, September 04, 2015

I am pleased to inform you that your Annual Renewal Request was reviewed by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved. No changes, amendments or addenda may be made in the protocol without the OHSN-REB's review and approval.

Renewal is valid for a period of one year. Approximately one month prior to that time, a single renewal form should be sent to the REB office.

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; and the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,


Raphael Singer, M.D.
Chairperson
Ottawa Health Science Network Research Ethics Board
/rt

Appendix C

- Clinical Data Forms -

Appendix C1: Pulmonary Function Test, Spirometry - CANVent Unit, Respiratory Services

Respiratory Services- CANVent UnitTOH Rehabilitation Centre
1201-505 Smyth Road, Ottawa ON K1H 8M2**Pulmonary Function Test
Spirometry**

Name: _____

ID: _____

Date: _____

Age: _____

DOB: _____

Gender: _____

Height(cm): _____

Weight(kg): _____

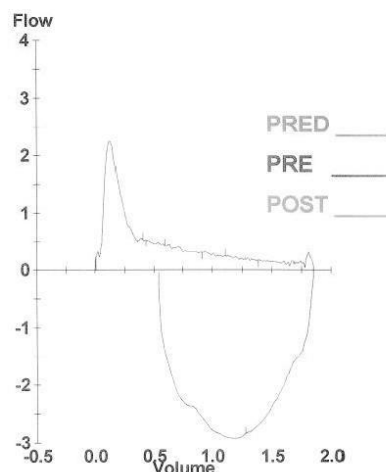
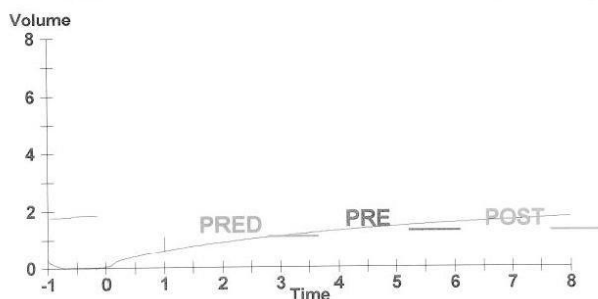
BMI: _____

Race: _____

Diagnosis: _____

Physician: _____

		Ref	(normal range)	Pre	% Ref	Post	% Ref	%Chg
Spirometry								
FVC	Liters	4.38	(3.4 - 5.4)	1.86	42			
• FEV1	Liters	3.38	(2.6 - 4.2)	0.62	18			
• FEV1/FVC	%	79	(69.1 - 88.2)	33				
✕ FEF25-75%	L/sec	2.82	(1.4 - 4.2)	0.23	8			
PEF	L/sec	8.65	(6.6 - 10.7)	3.29	38			



Comments: SpO2 92%, HR 105 on O2 2LPM

Interpretation:

- ☐ Normal ☐ Mild (FEV1 $\geq$ 80%)
☐ Restrictive ☐ Moderate (50% $\leq$ FEV1 < 80%)
☐ Obstructive ☐ Severe (30% $\leq$ FEV1 < 50%)
☐ Mixed ☐ Very Severe (FEV1 < 30%)

FEV1 Reversibility: ☐ No ☐ Yes ☐ Not Done

Interpretation: _____

Dr: _____

Appendix C2: Assessment, Daily Record, Discharge Summary – Physiotherapy

THE
REHABILITATION
CENTRE

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT

NAME: _____

CHART #: _____

D.O.B.: _____

(Page 1 of)

DIAGNOSIS: _____

Reason for Admission: _____

Date of Assessment: _____

DNR (Circle if Applicable)

History of Respiratory Problem:

Other Medical HX: _____

Surgical HX: _____

Employment Status: _____

Social History: _____

Home Setting:

☐ Bungalow

☐ Split

☐ 2 Storey

☐ Apt/Condo

☐ Elevator Access

_____ # of Steps Interior

_____ # of Steps Access

☐ Bathroom Main Floor

☐ Bathroom 2nd Floor

Medications:

☐ ANTIBIOTICS

☐ BRONCHODILATORS

☐ DIURETICS

☐ STEROIDS

☐ ANTI - HYPERTENSIVE

☐ COMBINATION BD + STEROID

☐ ANTI - ARRYTHMIC

☐ OXYGEN PRESCRIPTION

☐ OTHERS

Ventilation Issues:

☐ A.M. headaches

☐ c/o "fogginess"

☐ normal

THE
REHABILITATION
CENTRE

NAME:
CHART #:

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT (Page 2 of __)

FINDINGS

Clinical Measurements

Resting Vitals: Respiratory Rate _____ BP _____ Heart Rate _____ SpO₂ _____

Inspiratory/Expiratory Ratio _____ Weight _____ kg

Respiratory Muscle Strength ☐ MIP _____ cmH₂O ☐ MEP _____ cmH₂O

Blood Gases: PaO₂ _____ PaCO₂ _____

CPX

MAX HR: _____ Time: _____ End SpO₂: _____ End BP: _____ Borg: _____

Abnormalities: _____

Limitation: _____

Pulmonary Function

FEV₁ pre: _____ (%) post: _____ (%)

FVC pre: _____ (%) post: _____ (%)

BREATHING PATTERN

Upper Airway

- | | |
|---|---|
| ☐ Tracheal deviation | ☐ Tracheotomy |
| ☐ Mouth breather | ☐ Decreased vocal chord function |
| ☐ Blocked nasal passages | ☐ Normal |
- Comments: _____

Inspiratory Excursion

Intercostals

APICAL BREATHING ☐

UNABLE TO USE ☐

SYMMETRICALLY DECREASED ☐

MINIMAL USE ☐

ASYMMETRICALLY DECREASED ☐

IN-DRAWING ☐

NORMAL ☐

NORMAL ☐

Diaphragm

Accessory Neck Muscle

PARADOX ☐

CONTINUOUS ☐

REDUCED EXCURSION ☐

SEVERE EXERTION ☐

HEMI-DIAPHRAGM ☐

SLIGHT EXERTION ☐

NORMAL ☐

NEVER ☐

Assynchronous Breathing

☐ At rest ☐ NWB arms ☐ N/A

Expiration

FORCED EXPIRATION: ☐ No ☐ Yes _____

THE
REHABILITATION
CENTRE

NAME:

CHART #:

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT

(Page 3 of ____)

Posture	(Check Appropriate)	
KYPHOSIS		
SCOLIOSIS		
BARREL CHESTED		
PECTUS EXCAVATUM		
PECTUS CARINATUM		
SHORTENED ACCESSORY MUSCLES		Fixed ☐ yes ☐ no
FORWARD ROUNDED SHOULDERS		Fixed ☐ yes ☐ no
SLUMPED SITTING POSTURE		Fixed ☐ yes ☐ no
FORWARD LEANING POSTURE		Can come out of it and control breath? ☐ yes ☐ no
OTHER		

DISEASE MANAGEMENT

Cough	Yes ☐	No ☐
FREQUENT		
PATTERN		

Sputum	Yes ☐	No ☐
SPUTUM PRODUCTION		
SPUTUM COLOUR / TEXTURE		
SPUTUM QUANTITY TBSP/CUPS		
PATTERN		

Precipitating Factors	Cough	Dyspnea
COLD AIR		
EXERCISE		
HUMIDITY		
ENVIRONMENTAL AGENTS (NAME)		
ALLERGENS		
OTHER		

THE
REHABILITATION
CENTRE

NAME: _____

CHART #: _____

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT (Page 4 of)

Exacerbation

Frequency _____
Hospitalisations (#, reason) _____
ER Visits (#, reason) _____
Triggers _____

Knowledge of Disease Management Questionnaire Results

Medication: _____ / _____

Comments: _____

Recognising the Signs of Exacerbation: _____ / _____

Comments: _____

Exacerbation Management: _____ / _____

Comments: _____

Dyspnea Management : _____ / _____

Comments: _____

Biomechanic of Breathing : _____ / _____

Comments: _____

Exercise Strategies : _____ / _____

Comments: _____

Perceived Ability to Control Dyspnea: _____ / _____

Comments: _____

THE
REHABILITATION
CENTRE

NAME: _____

CHART #: _____

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT

(Page ____ of ____)

EXERCISE TOLERANCE

Functional Scan

ADL's	Independent	Assistance
SHOWER / BATH /DRESSING		
MEAL PREPARATION		
HOUSEKEEPING		
GROCERIES		

What is your mode of transportation? _____

Do you have an exercise program? ☐ No ☐ Yes What? _____

Have your outings been reduced in the last year? ☐ No ☐ Yes Why? _____

Have you lost the ability to do recreational activities? ☐ No ☐ Yes Which ones? _____

Of the previous activities what would you like to be able to resume? _____

Do you receive home care? ☐ No ☐ Yes What services? _____

How far can you walk? _____ Gait Aid ☐ No ☐ Yes Type? _____

Other physical factors which decrease your endurance? _____

Admission Exercise Values

Treadmill:

ANGLE _____ TIME _____ SPEED _____ O₂ _____ lpm

RESTING: SpO₂ _____ HR _____ BORG _____

POST: SpO₂ _____ HR _____ BORG _____

Schwinn Bicycle:

LEG BIKE: RPM _____ TIME _____ O₂ _____ lpm

RESTING: SpO₂ _____ HR _____ BORG _____

POST: SpO₂ _____ HR _____ BORG _____

ARM BIKE: RPM _____ TIME _____ O₂ _____ lpm

RESTING: SpO₂ _____ HR _____ BORG _____

POST: SpO₂ _____ HR _____ BORG _____

THE
REHABILITATION
CENTRE

NAME:

CHART #:

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT

(Page ____ of ____)

6 Minute Walk

TARGET HR _____ GAIT AID _____ O₂ _____ lpm

	MINUTES	Sp O ₂	HR	BORG	GYM LENGTHS
START	0				
STOP					
START					
STOP					
START					
STOP					

Time of first gym length _____ sec Number of stops _____

Total time walked _____ Total distance _____ metres

COMMENTS: _____

20 Minute Walk

TARGET HR _____ GAIT AID _____ O₂ _____ lpm

	MINUTES	Sp O ₂	HR	BORG	GYM LENGTHS
START	0				
STOP					

Time of 1st gym length _____ sec

Total time walked _____ Total distance _____ metres

COMMENTS: _____

Stairs

	Sp O ₂	HR	BORG	Number of Steps	
Start					CAN CARRY O ₂ ☐ Yes ☐ No ☐ N/A
Stop					RAILING ☐ Yes ☐ No

INDEPENDENT ☐ ASSISTANCE ☐ SUPERVISION ☐

COMMENTS: _____

THE
REHABILITATION
CENTRE

NAME: _____

CHART #: _____

PHYSIOTHERAPY DEPARTMENT

RESPIRATORY REHABILITATION ASSESSMENT (Page ____ of ____)

Musculoskeletal Scan (see guidelines for test positions and accepted norms)

STRENGTH: ☐ UE'S _____
☐ LE'S _____
 R.O.M.: ☐ UE'S _____
☐ LE'S _____
 OTHER: ☐ _____

GOALS AND ANALYSIS

Patient Outcome Goals

Marker _____	0 = (Unable to perform activity) Admission Status X										(Pre-Marker level) = 10 Predicted Goal O
1. _____	0	1	2	3	4	5	6	7	8	9	10
2. _____	0	1	2	3	4	5	6	7	8	9	10
3. _____	0	1	2	3	4	5	6	7	8	9	10

Physiotherapy Outcome Goals

1) ☐ BREATHING CONTROL

	Current	Goal
Independent	☐	☐
Supervision	☐	☐
Assistance	☐	☐

2) ☐ DISEASE MANAGEMENT

	Current	Goal
Independent	☐	☐
Supervision	☐	☐
Assistance	☐	☐

3) ☐ TRANSFER

	Current	Goal
Independent	☐	☐
Supervision	☐	☐
Assistance	☐	☐
Dependent	☐	☐

6) ☐ OTHER _____

4) ☐ EXERCISE TOLERANCE

☐ Treadmill	Angle _____ Speed _____ Time _____
☐ 20 minute walk	Distance _____ Time _____

☐ Stairs _____

	Current	Goal
Independent	☐	☐
Supervision	☐	☐
Assistance	☐	☐

5) ☐ ARM FUNCTION

	Current	Goal
Independent	☐	☐
Supervision	☐	☐
Assistance	☐	☐

THE
REHABILITATION
CENTRE
PHYSIOTHERAPY DEPARTMENT

NAME: _____

CHART #: _____

RESPIRATORY REHABILITATION ASSESSMENT

(Page ____ of ____)

Process Goals:

- ☐ Mechanics of breathing
☐ Shortness of breath

☐ Posture

☐ Knowledge base

☐ Lung hygiene

☐ Strength ☐ U/E ☐ L/E

☐ Endurance

☐ Environmental barriers

☐ Mechanics of transfer

☐ Pain Management

☐ Other _____

Summary of Treatment:

- ☐ Decrease use of accessory neck muscles
☐ Increase diaphragm movement
☐ Decrease forced expiration
☐ Increase lateral costal expansion
☐ Pursed lip breathing
☐ Decrease mouth breathing
☐ Relaxed breathing
☐ Normalize inspiratory/expiratory ratio
☐ Decrease respiratory rate

☐ Postural correction

- ☐ Review use of medication
☐ Administer Knowledge of Disease Questionnaires
☐ Education ☐ 1:1 ☐ group

☐ Thoracic mobility exercises

☐ Cough control

☐ Secretion clearance techniques

☐ PD ☐ Devices: which? _____

☐ Steam FETs (☐ cough / huff)

☐ other _____

☐ Progressive strengthening ☐ U/E ☐ L/E

☐ Walking class

☐ Gait aid prescription

☐ Pacing exercises

☐ Exercise modalities ☐ bicycle ☐ treadmill

☐ Monitor / adjust O₂

☐ Stairs

☐ Sit to stand

☐ Vertical transfers

☐ Pain modalities: _____

☐ Other _____

☐ The client / family consent to the above treatment plan. The following has been discussed with the client:

- What the treatment is
- Who will be providing the treatment
- The reasons why the client should have the treatment
- The important effects, risks, and side-effects of the treatment and the alternative physiotherapy treatment
- What might happen if the client does not have the treatment.

Signature of Physiotherapist

resp/assess1

Revised Sept. 2005

Date _____

THE REHABILITATION CENTRE
PHYSIOTHERAPY DEPARTMENT
RESPIRATORY SERVICE
PHYSIOTHERAPY DAILY RECORD

NAME: _____

CHART #: _____

WORK H.R. _____ (60-80%)

O₂ at rest _____ lpmO₂ on exs. _____ lpmO₂ at night _____ lpm

PRECAUTIONS:

DNR (Circle if applicable)

YEAR: _____

P.T. INITIALS															
DATE															
<u>TREADMILL</u> PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
GRADE (%)															
TIME (min)															
SPEED (mph)															
POST:															
<u>LEG BIKE</u> PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
TIME (min)															
SPEED (rpm)															
POST:															
<u>ARM BIKE</u> PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
TIME (min)															
SPEED (rpm)															
POST:															
TM exercises															
Breathing/ Cough Control															
Postural Correction															
Steam															
Flutter/PEP Acapella															
Other:															

Initials

Signature/Print Name

Initials

Signature/Print Name

--	--	--	--

THE REHABILITATION CENTRE
PHYSIOTHERAPY DEPARTMENT
RESPIRATORY SERVICE
PHYSIOTHERAPY DAILY RECORD

NAME: _____

CHART #: _____

WORK H.R. _____ (60-80%)

O₂ at rest _____ lpmO₂ on exs. _____ lpmO₂ at night _____ lpm

PRECAUTIONS:

DNR (Circle if applicable)

YEAR _____

P.T. INITIALS															
DATE															
TREADMILL PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
GRADE (%)															
TIME (min)															
SPEED (mph)															
POST:															
LEG BIKE PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
TIME (min)															
SPEED (rpm)															
POST:															
ARM BIKE PRE:	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB	SpO ₂	HR	SOB
TIME (min)															
SPEED (rpm)															
POST:															
TM exercises															
Breathing/ Cough Control															
Postural Correction															
Steam															
Flutter/PEP Acapella															
Other:															

Initials

Signature/Print Name

Initials

Signature/Print Name

THE
REHABILITATION
CENTRE

NAME:

CHART #:

PHYSIOTHERAPY DEPARTMENT

D.O.B:

RESPIRATORY PROGRAM DISCHARGE SUMMARY (Page 1 of 4)

Rehab Complete: ☐ Yes ☐ No Why: _____

DIAGNOSIS: _____

DATE OF ASSESSMENT: _____ DATE OF DISCHARGE: _____ From: ☐ IP ☐ OP

DISCHARGED TO: ☐ Home ☐ Community facility ☐ Other hospital ☐ OP care

FOLLOW-UP: ☐ Recheck Clinic ☐ Total Discharge ☐ Home Care ☐ Self Maintenance

☐ Lung Association ☐ Dovercourt ☐ Breathe Easy Physiotherapy ☐ Others _____

Home Program: see attached sheets: ☐ Yes ☐ No

PATIENT GOALS:

Marker _____	(Unable to perform activity) Admission Status X							Predicted Goal O	(Pre-marker level) Discharge Status _____			
1. _____	0	1	2	3	4	5	6	7	8	9	10	
2. _____	0	1	2	3	4	5	6	7	8	9	10	
3. _____	0	1	2	3	4	5	6	7	8	9	10	

PHYSIOTHERAPY OUTCOME GOALS:

1. ☐ BREATHING CONTROL ☐ Achieved ☐ Partially Achieved ☐ Not Achieved

☐ Independent ☐ Supervision ☐ Assistance

Comments: _____

2. ☐ DISEASE MANAGEMENT ☐ Achieved ☐ Partially Achieved ☐ Not Achieved

☐ Independent ☐ Supervision ☐ Assistance

Comments: _____

Education Questionnaire Results

Knowledge _____/_____ Ability to control breathe _____/_____

Comments: _____

THE
REHABILITATION
CENTRE
PHYSIOTHERAPY DEPARTMENT

NAME:

CHART #:

RESPIRATORY PROGRAM DISCHARGE SUMMARY (Page 3 of 4)

	O ₂ lpm	Sp O ₂	Pre		Stairs	Post		
			HR	Borg	Number Of Steps	Sp O ₂	HR	Borg
Adm								
D/C								

Carrying O₂: ☐ Yes ☐ No ☐ N/A Railing ☐ Yes ☐ No

Stairs: ☐ Independent ☐ Assistance ☐ Supervision

Comments:

5. ☐ ARM FUNCTION ☐ Achieved ☐ Partially Achieved ☐ Not Achieved
☐ Independent ☐ Supervision ☐ Assistance

6. ☐ OTHER:

DATA:

PULMONARY FUNCTION TESTS

Admission: FEV₁: (%) FVC: (%)

Discharge: FEV₁: (%) FVC: (%)

BODY WEIGHT: _____ kg

O₂ SUPPLEMENTATION

At rest _____ lpm

THE
REHABILITATION
CENTRE
PHYSIOTHERAPY DEPARTMENT

NAME:

CHART #:

RESPIRATORY PROGRAM DISCHARGE SUMMARY (Page 4 of 4)

Process Goals:

- ☐ Mechanics of breathing
☐ Shortness of breath

☐ Posture

☐ Knowledge base

☐ Lung hygiene

☐ Strength ☐ U/E ☐ L/E

☐ Endurance

☐ Environmental barriers

☐ Mechanics of transfer

☐ Pain Management

☐ Other

Number of Attendances: _____

Signature of Physiotherapist _____

Print Physiotherapist's Name _____

resp\disc.sum1.1 revised September 2009

Summary of Treatment:

- ☐ Decrease use of accessory neck muscles
☐ Increase diaphragm movement
☐ Decrease forced expiration
☐ Increase lateral costal expansion
☐ Pursed lip breathing
☐ Decrease mouth breathing
☐ Relaxed breathing
☐ Normalize inspiratory/expiratory ratio
☐ Decrease respiratory rate
☐ Other _____

☐ Postural correction

- ☐ Review use of medication
☐ Administer Knowledge of Disease Questionnaires
☐ Education ☐ 1:1 ☐ group

☐ Thoracic mobility exercises

☐ Cough control

☐ Secretion clearance techniques

☐ PD ☐ Devices: which? _____

☐ Steam FETs (☐ cough / huff)

☐ other _____

☐ Progressive strengthening ☐ U/E ☐ L/E

☐ Walking class

☐ Gait aid prescription

☐ Pacing exercises

☐ Exercise modalities ☐ bicycle ☐ treadmill

☐ Monitor / adjust O₂

☐ Stairs

☐ Sit to stand

☐ Vertical transfers

☐ Pain modalities: _____

☐ Other _____

Length of Stay: _____

Date _____

Appendix C3: Self-report Measures, Interview – Psychology

Due to copyright restrictions the Beck Depression Inventory-II could not be reproduced here.

The Self-Perceived Burden Scale is presented to patients as the “Care Receiving” measure.

It therefore appears as such in the appendix that follows.

BCS

NAME: _____ Age: _____ Sex: M() F() DATE: _____

Everyone experiences breathlessness at some point in their lives. Such experiences may include feeling short of breath, gasping and wheezing. People are often exposed to situations that may cause breathlessness such as over-exertion, exercise and illness. We are interested in the types of thoughts and feelings that you have when you are breathless. Listed below are thirteen statements describing different thoughts and feelings that may be associated with breathlessness.	Not At All	To A Slight Degree	To A Moderate Degree	To A Great Degree	All The Time
Using the following scale, please indicate the degree to which you have these thoughts and feelings when you are experiencing breathlessness. 0 = Not At All 1 = To A Slight Degree 2 = To A Moderate Degree 3 = To A Great Degree 4 = All The Time					
When I am short of breath...					
1. I worry all the time about whether the breathlessness will subside.....	0	1	2	3	4
2. I feel I can't go on.....	0	1	2	3	4
3. It's terrible and I think it's never going to get any better.....	0	1	2	3	4
4. It's awful and I feel that it overwhelms me.....	0	1	2	3	4
5. I feel I can't stand it anymore.....	0	1	2	3	4
6. I become afraid that the breathlessness will get worse.....	0	1	2	3	4
7. I keep thinking of other times I have been breathless.....	0	1	2	3	4
8. I anxiously want the breathlessness to go away.....	0	1	2	3	4
9. I can't seem to keep it out of my mind.....	0	1	2	3	4
10. I keep thinking about how out of breath I am.....	0	1	2	3	4
11. I keep thinking about how badly I want the breathlessness to stop.....	0	1	2	3	4
12. There's nothing I can do to reduce the intensity of the breathlessness.....	0	1	2	3	4
13. I wonder whether something serious might happen.....	0	1	2	3	4

ASI

NAME: _____ Age: _____ Sex: M() F() DATE: _____

INSTRUCTIONS	VERY LITTLE	A LITTLE	SOME	MUCH	VERY MUCH
1 It is important to me not to appear nervous.....	0	1	2	3	4
2. When I cannot keep my mind on a task, I worry that I might be going crazy.....	0	1	2	3	4
3. It scares me when I feel shaky.....	0	1	2	3	4
4. It scares me when I feel faint.....	0	1	2	3	4
5. It is important to me to stay in control of my emotions.....	0	1	2	3	4
6. It scares me when my heart beats rapidly.....	0	1	2	3	4
7. It embarrasses me when my stomach growls.....	0	1	2	3	4
8. It scares me when I am nauseous.....	0	1	2	3	4
9. When I notice that my heart is beating rapidly, I worry that I might have a heart attack.....	0	1	2	3	4
10. It scares me when I become short of breath.....	0	1	2	3	4
11. When my stomach is upset, I worry that I might be seriously ill.....	0	1	2	3	4
12. It scares me when I am unable to keep my mind on a task.....	0	1	2	3	4
13. Other people notice when I feel shaky.....	0	1	2	3	4
14. Unusual body sensations scare me.....	0	1	2	3	4
15. When I am nervous, I worry that I might be mentally ill.....	0	1	2	3	4
16. It scares me when I am nervous.....	0	1	2	3	4

Patient Health Questionnaire (PHQ-9)

NAME: _____ Age: _____ Sex: M() F() DATE: _____

INSTRUCTIONS Over the <i>last 2 weeks</i> , how often have you been bothered by any of the following problems? Use the scale at right as a basis for your answers.	Not at all	Several Days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.....	0	1	2	3
2. Feeling down, depressed or hopeless.....	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much.....	0	1	2	3
4. Feeling tired or having little energy.....	0	1	2	3
5. Poor appetite or overeating.....	0	1	2	3
6. Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down.....	0	1	2	3
7. Trouble concentrating on things such as reading the newspaper or watching television.....	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed or being so fidgety or restless that you have been moving around a lot more than usual.....	0	1	2	3
9. Thinking that you would be better off dead or that you want to hurt yourself in some way.....	0	1	2	3
If you checked off any problem on this questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? Not difficult at all <input style="width: 20px; height: 15px;" type="checkbox"/> Somewhat difficult <input style="width: 20px; height: 15px;" type="checkbox"/> Very difficult <input style="width: 20px; height: 15px;" type="checkbox"/> Extremely Difficult <input style="width: 20px; height: 15px;" type="checkbox"/>				

COPD Self-Efficacy Scale

NAME: _____ Age: _____ Sex: M() F () DATE: _____

INSTRUCTIONS Please read each numbered item below, and determine how confident you are that you can manage breathing difficulty or avoid breathing difficulty in that situation. Use the scale at right as a basis for your answers.	Very Confident	Pretty Confident	Somewhat Confident	Not Very Confident	Not At All Confident
1. When I become too tired.....	1	2	3	4	5
2. When there is humidity in the air.....	1	2	3	4	5
3. When I go into cold weather from a warm place.....	1	2	3	4	5
4. When I experience emotional stress or become upset.....	1	2	3	4	5
5. When I go up stairs too fast.....	1	2	3	4	5
6. When I try to deny that I have respiratory difficulties.....	1	2	3	4	5
7. When I am around cigarette smoke.....	1	2	3	4	5
8. When I become angry.....	1	2	3	4	5
9. When I exercise or physically exert myself.....	1	2	3	4	5
10. When I feel distressed about my life.....	1	2	3	4	5
11. When I feel sexually inadequate or impotent.....	1	2	3	4	5
12. When I am frustrated.....	1	2	3	4	5
13. When I lift heavy objects.....	1	2	3	4	5
14. When I begin to feel that someone is out to get me.....	1	2	3	4	5
15. When I yell or scream.....	1	2	3	4	5
16. When I am lying in bed.....	1	2	3	4	5
17. During very hot or very cold weather.....	1	2	3	4	5
18. When I laugh a lot.....	1	2	3	4	5
19. When I do not follow a proper diet.....	1	2	3	4	5
20. When I feel helpless.....	1	2	3	4	5

COPD Self-Efficacy Scale ***...Continued***

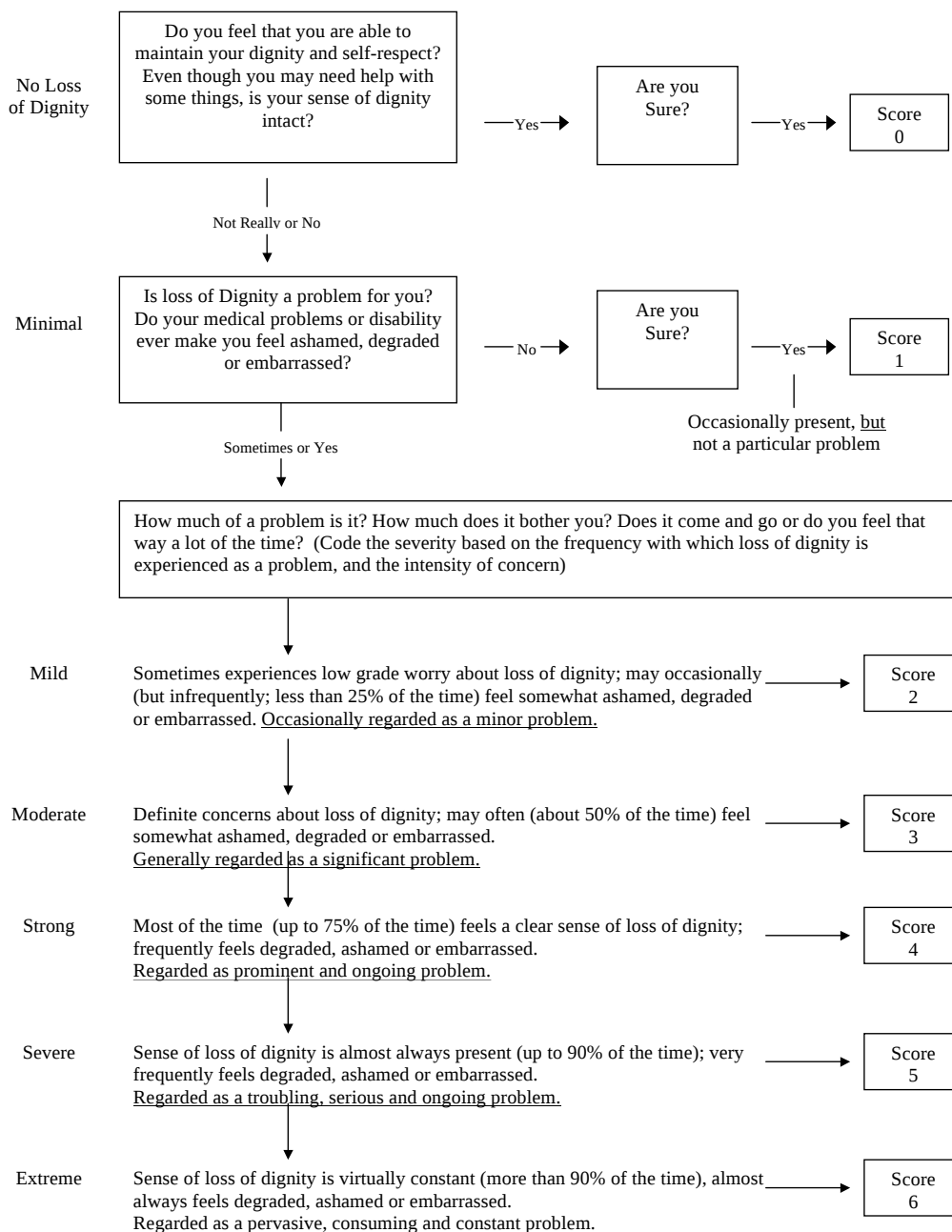
INSTRUCTIONS Please read each numbered item below, and determine how confident you are that you can manage breathing difficulty or avoid breathing difficulty in that situation. Use the scale at right as a basis for your answers.	Very Confident	Pretty Confident	Somewhat Confident	Not Very Confident	Not At All Confident
21. When I drink alcoholic beverages.....	1	2	3	4	5
22. When I get an infection (throat, sinus, colds, the flu, etc.).....	1	2	3	4	5
23. When I feel detached from everyone and everything.....	1	2	3	4	5
24. When I experience anxiety.....	1	2	3	4	5
25. When I am around pollution.....	1	2	3	4	5
26. When I overeat.....	1	2	3	4	5
27. When I feel down or depressed.....	1	2	3	4	5
28. When I breathe improperly.....	1	2	3	4	5
29. When I exercise in a room that is poorly ventilated.....	1	2	3	4	5
30. When I am afraid.....	1	2	3	4	5
31. When I experience the loss of a valued object or a loved one.....	1	2	3	4	5
32. When there are problems in the home.....	1	2	3	4	5
33. When I feel incompetent.....	1	2	3	4	5
34. When I hurry or rush around.....	1	2	3	4	5

Care Receiving

NAME: _____ Age: _____ Sex: M() F() DATE: _____

INSTRUCTIONS	None of the time	A little of the time	Some of the time	Most of the time	All of the time
We would like to know more about how you feel about receiving care. In this questionnaire, the term “significant other” pertains to your spouse, partner, or family member. Please rate each statement on a scale of how often you feel this way, by circling your response. Please consider your answers carefully, as we would like you to be as open as possible.					
1. I worry that the health of my significant other could suffer as a result of caring for me.....	0	1	2	3	4
2. I worry that my significant other is overextending himself/herself in helping me...	0	1	2	3	4
3. I am concerned that it costs my significant other a lot of money to care for me...	0	1	2	3	4
4. I feel guilty about the demands that I make on my significant other.....	0	1	2	3	4
5. I am concerned that I am “too much trouble” to my significant other.....	0	1	2	3	4
6. I am concerned that because of my illness, my significant other is having to do too many things at once.....	0	1	2	3	4
7. I am confident that my significant other can handle the demands of caring for me	4	3	2	1	0
8. I think that I make things hard on my significant other.....	0	1	2	3	4
9. I feel I am a burden to my significant other.....	0	1	2	3	4
10. I am concerned that my significant other is helping me beyond their capacity....	0	1	2	3	4
11. When my stomach is upset, I worry that I might be seriously ill.....	0	1	2	3	4
12. It scares me when I am unable to keep my mind on task.....	0	1	2	3	4
Please indicate how much you agree with the following statements by circling your response.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
13. I do not discuss my feelings with my significant other as I do not want to cause him/her distress.....	0	1	2	3	4
14. I avoid asking for help from my significant other so that I do not burden him/her.....	0	1	2	3	4

LOSS OF DIGNITY



Appendix D

- Chart Review Data Collection Form -

ID: _____

DATE OF ASSESSMENT: _____ DATE OF DISCHARGE: _____

REHAB COMPLETE: ☐ Yes ☐ No Reason: _____MEDICATIONS: ☐ None ☐ Broncho ☐ Steroids ☐ BD + ST ☐ O₂ Rx

		PRE					6-MINUTE WALK				POST		
	O ₂ lpm	Aids	SpO ₂	HR	Borg		Sec/ Length	Time	Stops	Dist. (m)	SpO ₂	HR	Borg
ADM													
D/C													

		PRE					NON-STOP WALK				POST		
	O ₂ lpm	Aids	SpO ₂	HR	Borg		Sec/ Length	Time	Stops	Dist. (m)	SpO ₂	HR	Borg
ADM													
D/C													

		PRE					TREADMILL			POST			
	O ₂ lpm	SpO ₂	HR	Borg	BP		Grade %	Speed	Time	SpO ₂	HR	Borg	BP
ADM													
D/C													

		PRE					LEG BIKE		POST			
	O ₂ lpm	SpO ₂	HR	Borg	BP		Speed	Time	SpO ₂	HR	Borg	BP
ADM												
D/C												

		PRE					ARM BIKE		POST			
	O ₂ lpm	SpO ₂	HR	Borg	BP		Speed	Time	SpO ₂	HR	Borg	BP
ADM												
D/C												

		PRE			STAIRS	POST		
	O ₂ lpm	SpO ₂	HR	Borg	Number of Steps	SpO ₂	HR	Borg
ADM								
D/C								

		FEV ₁	FEV ₁ (%)	FVC	FVC (%)
ADM					
D/C					

ID:

NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

VOCATIONAL STATUS		
ADM	D/C	
		Paid employment – Full time
		Paid employment – Part time
		Paid employment – Adjusted/modified
		Unpaid employment – Full time
		Unpaid employment – Part time
		Unpaid employment – Adjusted/modified
		Student – Full time
		Student – Part time
		Student – Adjusted/modified
		Unemployed
		Retired – for age
		Retired – for disability
		Not available, temporarily
		Asked, unknown
		None of the above

FUNCTIONAL INDEPENDENCE MEASURE (FIM)					
		ADM	D/C		
SELF-CARE					
Eating					
Grooming					
Bathing					
Dressing Upper Body					
Dressing Lower Body					
Toileting					
SPHINCTER					
Bladder Management					
Bowel Management					
TRANSFERS					
Bed/Chair/Wheelchair					
Toilet					
Tub, Shower					
LOCOMOTION				w/	w/o
Walk/Wheelchair (W/WC)				If score of 5; helper?	
Stairs					
COMMUNICATION				ADM	D/C
Comprehension				Auditory, Visual, Both	
Expression				Vocal, Non-vocal, Both	
SOCIAL COGNITION					
Social Interaction					

ID:

Problem Solving		
Memory		
Glasses/Hearing Aid Flag		

CIHI COGNITIVE ASSESSMENT		
	ADM	D/C
Communicating: Verbal or Non-verbal Expression		
Communicating: Written Expression		
Communication: Auditory or Non-auditory Comprehension		
Communication: Reading Comprehension		
Impact of Pain		
Presence of Pain		
Intensity of Pain		
Impact of Activities		
Meal Preparation (optional)		
Light Housework (optional)		
Heavy Housework (optional)		
Financial Management		
Orientation		
General Health Status		
Respondent		
General Health Status		

HEIGHT & WEIGHT

ADM: Height (cm): _____ Weight (kg): _____

D/C: Height (cm): _____ Weight (kg): _____