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## Symptom Experience and Treatment Delay during Acute Exacerbation of Chronic Obstructive Pulmonary Disease: A Dissertation

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Symptom Experience and Treatment Delay  
during  
Acute Exacerbation of Chronic Obstructive Pulmonary Disease

A Dissertation Presented

by

Elizabeth Danells Chin

Submitted to the Graduate School of Nursing  
University of Massachusetts Worcester  
in partial fulfillment  
of the requirements for the degree of

Doctor of Philosophy

Nursing

2012

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University of Massachusetts Worcester  
Graduate School of Nursing

University of Massachusetts Worcester

Graduate School of Nursing

*Symptom Experience and Treatment Delay during Acute Exacerbation of COPD*

A Dissertation Presented

By

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## Dedication

This dissertation is dedicated to my beautiful sons who inspire me to be the best that I can be each and every day. As much as a mother raises her children, so do children raise their mother. You have taught me many things as I have watched you grow into the fine young men you have become.

Andrew- your strong character, intelligence, inquisitiveness and enthusiasm for learning have challenged me to never stop growing personally or professionally. Ryan- your compassion, tenacity and perseverance, against all odds, have motivated me to keep moving toward my goals, even when the goals seems unreachable. Thank you for inspiring me to accomplish this particular goal, completion of my doctoral degree.

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I would never have completed this doctoral program without the support and encouragement of my colleague, classmate and friend Deborah Armstrong. How fitting it was to start and finish the program together, right down to the final defense day! Thank you for taking this journey with me.

Finally, I would like to thank my family and dear friends who have been there for me throughout all of life's challenges. Bless you for keeping me going!

## Abstract

Chronic obstructive pulmonary disease (COPD) is a major health problem in the United States. Acute exacerbations of COPD are primarily responsible for the physical, psychological and economic burden of this disease. Early identification and treatment of exacerbations is important to improve patient and healthcare outcomes. Little is known about how patients with COPD recognize an impending exacerbation and subsequently decide to seek treatment. The purpose of this qualitative descriptive study was to explore and describe symptom recognition and treatment delay in individuals experiencing an acute exacerbation of chronic obstructive pulmonary disease (COPD). Leventhal's Common Sense Model of illness representation undergirded this study.

Using semi-structured interviews, adults hospitalized with an acute exacerbation of COPD were asked to describe their symptom experience and self care behaviors, including treatment seeking, in the days to weeks prior to hospitalization. Data analysis revealed one main theme: *Recognizing, responding and reacting to change*, and six subthemes: *Something's coming*, *Here we go again*, *Seeking urgent treatment*, *Riding it out*, *Not in charge anymore* and *My last day* that richly described the COPD exacerbation experience. The study revealed that patients experience an illness prodrome prior to exacerbation and have a recurrent exacerbation symptom pattern that was self-recognized. Treatment seeking was most influenced by the speed and acuity of exacerbation onset, severity of breathlessness, fears of death, nature of patient-provider relationship and the perception of stigmatization during prior healthcare encounters. These findings are important for the development of interventions to improve patient recognition and management of COPD exacerbations in the future

## Table of Contents

List of Tables	ix
List of Figure	x
Chapter 1 Literature Review	1
Introduction	1
COPD epidemiology	2
COPD diagnosis, classification, manifestations	4
Burden of COPD	7
COPD morbidity and mortality	10
COPD exacerbation manifestations, diagnosis, and classification	12
Burden of COPD exacerbation	22
Symptom recognition	24
Prodromal symptom recognition	26
Treatment Delay	27
Purpose and specific aims	31
Chapter 2 Theoretical framework	32
Components of CSM	35
Use of CSM in research	38
Operational definitions	46
Chapter 3 Methods	48
Setting and sample	49



Data management	56
Data Analysis	57
Trustworthiness	59
Ethical consideration and protection of human subjects	62
Chapter 4 Results	65
Demographic data	65
Themes and subthemes	71
Chapter 5 Discussion	93
Implications for research	101
Implications for practice	103
Implications for health policy	105
Limitations	106
References	109
Appendices	
Appendix A. Demographic Data Sheet	132
Appendix B. Interview Guide	133

## List of Tables

Table 1. Gold Stages of COPD Severity	5
Table 2. COPD Symptoms Experienced Daily	5
Table 3. BODE Index	11
Table 4. Bode Stage	11
Table 5. COPD Exacerbation Symptoms	14
Table 6. Anthonisen Exacerbation Typology	18
Table 7. CSM use in research	39
Table 8. Sample Characteristics for Categorical Variables	67
Table 9. Sample Characteristics for Continuous Variables	68
Table 10. Exacerbation Symptoms with Anthonisen Typology Classification	72

## List of Figures

<i>Figure 1: The Common Sense Model of Illness</i>	34
<i>Figure 2: Research Procedures</i>	54
<i>Figure 3: Themes and Subthemes</i>	74

## **Introduction**

Chronic obstructive pulmonary disease (COPD) is a chronic, debilitating illness that has rapidly progressed into a major health problem. It is currently the third leading cause of death in the United States (Murphy, Xu & Kochanek, 2010). Despite declines in mortality from cardiovascular disease, stroke and cancer, morbidity and mortality related to COPD continue to rise (Mannino et al., 2000). The prevalence of COPD in the US is 24 million, however it is estimated that the number is actually much higher (U.S Department of Health and Human Services [USDHHS], 2010). This suggests that more than 13.9 % of the population has impaired lung function consistent with the diagnosis of COPD (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2004; Mannino, 2002), representing a two-fold increase in prevalence over the last two decades (Mannino et al., 2000). In 2000, COPD was responsible for 119,000 deaths, 726,000 hospital admissions, 1.5 million emergency room visits and 8 million outpatient and primary care visits. This translates into 37 billion dollars a year in direct and indirect COPD related costs (Center for Disease Control and Prevention [CDC], 2002). According to the American Thoracic Society (ATS), this figure is estimated to reach an unprecedented \$832 billion dollars by the year 2020 (Lee, Sullivan & Buist, 2006). Acute exacerbations of COPD are a major cause of hospitalization and overall disease cost. Many individuals experience four to five exacerbations a year (Goodridge, 2006; Izquierdo, Barcina, Jimenez, Munoz & Leal, 2009) and the effects can have a devastating physical and emotional impact on their lives (Goodridge, 2006; Izquierdo et al., 2009; O'Neill, 2002; Seemungal et al., 1998). Studies demonstrate that individuals who receive treatment at the onset of exacerbation recover sooner, and experience better health-related quality of life (HRQOL) and functional performance than individuals who delay treatment (Bourbeau & Nault, 2007; Wilkinson, Donaldson, Hurst,

Seemungal, & Wedzicha, 2004). Early recognition, timely health practitioner consult and prompt treatment for an exacerbation would reduce the economic impact of COPD (Wilkinson et al., 2004).

There has been little research on an individual's awareness of the early prodromal signs of acute exacerbation of COPD or recognition of individual symptom patterns representing acute worsening of baseline health (Caverley et al., 2005; Kessler et al., 2006; Wilkinson et al., 2004). Why patients with COPD delay seeking treatment when they experience symptoms indicative of an acute exacerbation is also unknown (Bourbeau & Nault, 2007; Langsetmo, Platt, Ernst, & Bourbeau, 2008; Wilkinson et al., 2004). Therefore, the purpose of this qualitative descriptive dissertation study was to explore the COPD exacerbation experience with a primary focus on prodromal symptoms and symptom pattern recognition in addition to factors that delay treatment-seeking.

This chapter describes COPD and the impact of acute exacerbation on the health status of individuals with COPD. This chapter also reviews current research studies and expert reviews on symptom recognition and treatment delay in chronic illnesses with characteristics similar to COPD.

### **COPD epidemiology**

Chronic Obstructive Pulmonary Disease (COPD) is a lung disease characterized by airflow obstruction that is not fully reversible. The airflow limitation is progressive and associated with an abnormal inflammatory response in the lungs when exposed to noxious inhalants (Celli, MacNee et al., 2004). In the US, the older terms chronic bronchitis and emphysema are included in the newer diagnostic term, COPD (WHO, 2011). Patients typically have components of both these conditions in their disease presentation. Emphysema

manifestations are the consequence of weakened alveolar walls with subsequent loss of elasticity and recoil, resulting in air trapping, and impaired gas exchange. An estimated 3.1 million Americans have been diagnosed with emphysema, 58% of those are male. The manifestations of chronic bronchitis are due to airway inflammation and scarring, resulting in excess mucus production that restricts airflow. Chronic bronchitis affects an estimated 9.1 million Americans, and females are two times more likely than their male counterpart to experience chronic bronchitis as the predominant component of their COPD (American Lung Association, 2011). According to the 2007 National Health Interview Survey, Americans diagnosed with COPD are more likely to be White, less than 65 year old (70%), have a high school education or lower, classified in a lower socio-economic status, married or co-habiting (Pleis & Lucas, 2009).

Although the predominant and most troublesome symptoms of COPD involve the respiratory system, COPD is a systemic disease with manifestations that also involve the cardiovascular, musculoskeletal, and immune systems (Celli, 2006; Punturieri, Croxton, Weinmann, & Kiley, 2007). This multisystem involvement contributes to the significant morbidity and mortality associated with this disease (Celli, 2006; Yu-Isenberg, Vanderplas, Chang & Shah, 2005).

The most important risk factor for COPD is smoking, although one out of every six individuals with COPD has never smoked (Mannino, Gagnon, Petty, & Lydick, 2000). In non-smokers, risk factors include occupational and environmental exposure, severe childhood respiratory infections and genetic factors (Rabe et al., 2007). The pathophysiologic changes associated with COPD usually begin 10 years after an individual initiates smoking, although symptoms are seldom noticeable in these early stages. Symptoms typically become more noticeable after the age of 40, with shortness of breath on exertion emerging first, which is often

interpreted as a sign of aging. These factors contribute to the under diagnosis of COPD in the early mild stages and missed opportunities for early treatment (American Lung Association, 2011; Rabe et al., 2007). Gradual deterioration and increased symptom severity occur over time, ultimately leading to COPD diagnosis long after lung function has declined and HRQOL has been diminished (Donaldson & Wedzicha, 2006). Most individuals are diagnosed in the fourth through sixth decades of life (American Lung Association, 2011; Anto, Vermeire, Vestbo, & Sunyer, 2001).

### **COPD diagnosis, classification and manifestations**

COPD has a heterogeneous clinical presentation, and each individual has a symptom pattern that is typical for them (Cicutto, Brooks & Henderson, 2004; McCarley, Hanneman, Padhye & Smolensky, 2007; Wedzicha, 2000), which is related to the predominant component (chronic bronchitis or emphysema) of their COPD pathology (Rennard et al., 2002; McCarley et al., 2007; Wedzicha, 2000). Dyspnea is the hallmark symptom of COPD, although in some individuals cough may be present well before dyspnea emerges. Dyspnea worsens as lung function deteriorates across the disease trajectory, and is the major cause of disability associated with COPD. It is typically the emergence of persistent dyspnea that provides the impetus for health care consult, leading to a COPD diagnosis (Rabe et al., 2007).

COPD is diagnosed based on spirometry and staged according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria based on post-bronchodilator percent predicted forced expiratory volume in 1 second Forced Expiratory Volume (FEV1), and/or FEV1/FVC (forced vital capacity) ratio. The spirometric cut-points and corresponding stages recommended by the GOLD committee for classification of COPD disease severity (Rabe et al., 2007) are listed in Table 1.

**Table 1***GOLD stages of COPD severity*

Stage	FEV1 Parameter	FEV1/FVC %
Stage I: Mild	FEV1 $\geq$ 80% predicted	FEV1/FVC < 0.70
Stage II: Moderate	FEV1 < 80% predicted	FEV1/FVC < 0.70
Stage III: Severe	FEV1 < 50% predicted	FEV1/FVC < 0.70
Stage IV: Very Severe	FEV1 < 30% predicted or FEV1 < 50% predicted plus chronic respiratory failure	FEV1/FVC < 0.70

Additional daily symptoms (Table 2) experienced by individuals with COPD include cough, sputum production, wheeze and fatigue. Cough and sputum production are more frequently observed in individuals with a predominant chronic bronchitis component in their COPD presentation. Chest tightness and sleep disturbance were also reported, but at a lower frequency (Barnett, 2005; Barr et al., 2005; Calverley et al., 2005; Chen, Chen, Lee, Cho, & Weng, 2008; Donaldson, Wilkinson, Hurst, Perera, & Wedzicha, 2005; Gift & Shepard, 1999; Jablonski, Gift, & Cook, 2007; Miravittles, Anzueto, Legnani, Forstmeier, & Fargel, 2007; O'Neill, 2002; Reishtein, 2004; Seemungal, Donaldson, Bhowmik, Jeffries, & Wedzicha, 2000).

**Table 2***COPD Symptoms Experienced Daily*

Author	Purpose	Sample	Study Design	Usual Symptoms
Barnett (2004)	Pt experience of COPD	N=10	Phenomenological	Dyspnea fatigue cough
Barr et al. (2005)	Physician and patient perception of COPD	N=1023	Survey	dyspnea 90% cough 75% sputum 71% sleep disturbance 60%
Calverley et al. (2005)	Relationship between symptoms and treatment during exacerbation	N=796 mean age 64 FEV1 36%	Secondary analysis clinical trial data	Rate 0-4 (min-max) SOB 1.9 Cough 1.4 chest tightness 1.2



Author	Purpose	Sample	Study Design	Usual Symptoms
Chen et al. (2008)	Self-management behaviors	N= 18 mean age 74	Qualitative description	Dyspnea cough sputum
Donaldson et al. (2005)	Exacerbations and time spent outdoors	N=147 mean age 68 M101/F46 FEV1 40.9%	Prospective cohort	dyspnea 55% wheeze 68% cough 54% sputum 47.6%
Gift & Shepard (1999)	Symptoms experience in COPD- determine differences between men and women	N= 104 mean age 60 56M/48W FEV1 23%	Correlational, predictive	dyspnea 100 % fatigue 58 % cough 55 % dry mouth 50%
Jablonski et al. (2007)	Evaluate Memorial Symptom Scale for use with COPD	N=72 mean age FEV1 30%	Secondary data analysis	SOB fatigue cough difficulty sleeping
Kinsman et al. (1983)	Determine normative data for frequency of occurrence of each Bronchitis-Emphysema Symptom Checklist (BESC) symptom category	N= 146 mean age 63 85M/61F	Tool development	dyspnea 88% fatigue 92% sleep disturbance 74% sputum 79%
O'Neill (2002)	Explore illness representation in women	N= 21 mean age 67 F 21	Qualitative description	dyspnea 100% fatigue 47% sleep disturbance
Reishtein (2004)	Relationship between symptoms and functional performance	N=100 mean age 67 M77/F23 FEV1 41%	Correlational	Dyspnea fatigue sleep disturbance
Seemungal et al. (2000)	Time course and recovery of exacerbation	N=101 mean age 67.5 FEV1 41.9%	Prospective cohort	dyspnea 40.6% wheeze 34.7% cough 54.5% sputum 58.4%

COPD symptoms vary in intensity from hour to hour and day to day (Meek, Lareau, & Anderson, 2001; Rabe et al., 2007). A unique pattern of symptoms characterize each patient's clinical presentation, and include temporal variations of dyspnea and fatigue symptoms (McCarley, Hanneman, Padhye & Smolensky, 2007). This day-to-day variation complicates symptom awareness (Adams, Chavannes, Jones, Ostergaard & Price, 2006). The symptoms

experienced by individuals with COPD are not only physically distressing, but have psychological and social consequences that contribute to the overall burden of this disease (Dodd et al., 2001).

### **Burden of COPD**

In a cross-sectional study ( $N=3619$ ) on the burden of COPD, dyspnea was reported to constitute the greatest burden for individuals (Izquierdo et al., 2009). This was supported by participants in Adams, Chavannes, Jones and Ostergaard's (2006) grounded theory study ( $N=23$ ), O'Neill's (2002) qualitative descriptive study ( $N=21$ ) and Fraser, Kee & Minick's (2006) phenomenological study ( $N=10$ ). Participants in these qualitative studies described how dyspnea invaded every aspect of their daily lives (Fraser et al., 2006) impacting even the simplest of daily living activities, such as moving between different levels in their homes (Adams et al., 2006). They also described an illness that was unpredictable, especially with fluctuating levels of physical endurance and dyspnea, (Adams et al., 2006) and took up too much time related to symptom management and trying to get well (Cicutto et al., 2004).

Fatigue, the perception of mental or physical exertion, is also common in COPD. In a descriptive study of the prevalence, duration and severity of fatigue among patients with COPD, Theander and Unosson (2004) collected data using the Fatigue Impact Scale (FIS) (Fisk, Ritvo, Ross, Haase, Marrie, Schleich, 1994). The questionnaire was completed by 36 patients and 37 age- and sex-matched controls. Daily fatigue was reported by 47.2% of patients with COPD, compared to 13.5% of the controls. Fatigue duration was between 6 and 24 hours in 52.7% of patients, and 18.9% of control subjects. Forty-four percent of the patients rated fatigue as the most bothersome, or one of the most bothersome symptoms. The impact of fatigue on cognitive, physical and psychosocial functioning were also greater in the patient group than the control

group, as indicated by higher scores in the corresponding FIS dimensions (9.5, 19.2, 30.9 vs. 5.7, 6.8, 10.2, respectively, t-test:  $p < .05$ )

Significant correlations between fatigue and dyspnea have been reported in several studies of men and women with moderate to severe COPD (Baghai-Ravary et al. (2009)  $r = .34$ ,  $p < .001$ ,  $N=107$ ); Gift & Shepard (1999)  $r = .63$ ,  $p < .01$ ,  $N=143$ ; Kinsman et al. (1983)  $r = .76$ ,  $p < .05$ ,  $N= 146$ ). Reishtein (2005) also reported a significant relationship between fatigue and functional performance ( $r = -.54$ ,  $p < .001$ ) in a sample of 77 men and 23 women with moderate to severe COPD. Furthermore, Baghai-Ravary et al. (2009) reported that fatigue was not related to FEV1 ( $r = .1$ ,  $p = .3$ ) or GOLD stage (ANOVA  $p = .07$ ), suggesting that the experience of fatigue was not associated with disease severity.

Studies have also shown that fatigue in COPD is associated with depression and reduced health status (Al-shair et al., 2009; Baghai-Ravary et al., 2009; Nishimura et al., 2009; Webster, Cella & Yost, 2003). Fatigue, measured on the chronic illness therapy-fatigue scale (FACIT-fatigue) (Webster et al., 2003), was significantly associated with higher depression scores on the Center for Epidemiology Studies Depression scale (CES-D) (Radloff, 1977). Greater fatigue on the FACIT-fatigue (mean 27.7 vs. 40) was associated with clinical depression, defined as a CES-D score  $\geq 16$  ( $r = -.59$ ,  $p < .001$ ) (Baghai-Ravary, 2009). Fatigue was also associated with decreased time outdoors ( $r = -.43$ ,  $p < .001$ ) (Baghai-Ravary, 2009), which has been shown to also increase depression and HRQOL (Donaldson et al., 2005). The association between fatigue and HRQOL was evident in the higher scores on the St Georges Respiratory Questionnaire (SGRQ) (Jones, Quirk, Baveystock, 1991), which were significant for total score ( $r = .61$ ,  $p < .001$ ) as well as the activity, impact and symptom subscales ( $r = -.44$ ;  $r = -.65$ ;  $r = -.36$ ; all,  $p < .001$ ) (Baghai-Ravary et al., 2009).

Al-shair et al. (2009) reported a significant relationship between depression and performance on a 6-minute walk distance test (6MWD) ( $r = 0.33, 0.4, p < .001$ ) even after controlling for severity based on FEV1. Depression on the CES-D was a predictor of poor exercise tolerance (OR 1.11, 95% CI 1.05-1.18,  $p < .001$ ) as well as depression on the BASDEC (Adshead, Day, Pitt, 1992) (OR 1.25, 1.08-1.42,  $p = .001$ ). A relationship between depression and poor health status was also demonstrated and was more pronounced than the impact of severe dyspnea on health status.

Depression and anxiety are common features of COPD with higher rates of depression and anxiety reported in individuals with COPD compared to the general population (Putman-Casdorph & McCrone, 2009). Al-shair et al. (2009) identified depression in 17% of subjects ( $N=122$ ) using the BASDEC, and 21% of patients using the CES-D assessment tool. Funk et al. (2009) identified higher levels of depression (51%) in their subjects ( $N=122$ ), as well as a high prevalence of anxiety (51% males, 57% females). The presence of co-morbid anxiety was also noted in 78% of depressed individuals, and co-morbid depression in 78% of anxious individuals. According to de Voogd et al. (2009), depression impairs self care resulting in a lower body mass index (BMI), poor compliance with treatment plan and poor help-seeking behavior. In a sample of 121 men and women, depression was also associated with continued smoking behavior ( $r = .27, p < .01$ ) and mortality (OR 1.93, 95% CI 1.12-3.33), independent of other factors (de Voogd et al., 2009). As COPD severity increases, social interaction and physical activity begin to decline, leading to increased dependence, social and emotional isolation, and poor HRQOL. These physical and emotional challenges often lead to feelings of frustration and depression (Cicutto et al., 2004; Fraser et al., 2006). In a correlational study ( $N=92$ ) Andenaes, Kalfoss and Wahl (2004) reported that longer disease duration was related to more physical symptoms and

additional psychosocial impact. On regression analysis, psychological distress, measured by the Hopkins Symptom Checklist (HSCL) (Derogatis, Lipman, Rickels Uhlenhuth & Covi, 1974), significantly correlated with St. Georges Respiratory Questionnaire (SGRQ) impact scores ( $r = .41$ ,  $p < .001$ ), however not with the symptom ( $r = .01$ ) or activity scores ( $r = .14$ ), indicating that psychological distress was associated with the impact of the disease rather than with the symptoms themselves.

The impact of COPD on social activity and work productivity was evident in the findings of a multinational survey study ( $N=3265$ ) conducted in North America and six European countries (Rennard et al., 2002). More than one-third (35.7%) of subjects reported they were unable, or had limited ability to work. In subjects who did work, 45.3% reported work time loss related to their COPD symptoms. All subjects reported some level of impact on ADLs, with middle age subjects reporting functional limitations similar to older adults in the area of recreation (65%), socialization (40%), household chores (50%), family activities (38%) and sexual relationships (35%). Only normal physical activity remained a greater burden for individuals  $> 65$  (67%) than those  $< 65$  (56%) due to their COPD (Rennard et al., 2002). This may have been related to the additive effect of aging; however the study design did not control for these confounding variables. Regardless, the disease impact on normal daily living and important age-related developmental tasks is significant.

### **COPD morbidity and mortality**

The body-mass, airflow obstruction, dyspnea and exercise capacity (BODE) index (Celli, Cote et al., 2004) is a multidimensional grading system that assesses the respiratory and systemic expressions of COPD to categorize and predict outcomes in this population. Individuals are scored on four criteria, receiving a score of 0-4 in each criteria area for a total score range of 0-

10 (Table 3). Individuals are then staged according to their BODE index score (Table 4).

Higher BODE index stages are associated with greater morbidity and mortality. In a prospective cohort study (N=625) designed to validate the BODE index, individuals with higher BODE scores were at higher risk for death; the hazard ratio for death from any cause per one-point increase in the BODE score was 1.34 (95 percent confidence interval, 1.26 to 1.42;  $p < .001$ ), and the hazard ratio for death from respiratory causes was 1.62 (95 percent confidence interval, 1.48 to 1.77;  $p < .001$ ). The BODE index is considered to be superior to the GOLD classification for assessing morbidity (Pauwels et al., 2001) and predicting in-hospital mortality following COPD exacerbation (Celli, Cote et al., 2004).

**Table 3**

*BODE Index*

	Points on BODE Index			
	0	1	2	3
FEV1 % predicted	≥ 65	50-64	36-49	≤ 35
Distance walked in 6 minutes	≥ 350	250-349	150-249	≤ 149
MMRC dyspnea scale	0-1	2	3	4-5
BMI	≥ 21	≤ 21		

**Table 4**

*BODE Stage*

Stage	Index Score
I	0-2
II	3-4
III	5-7
IV	8-12

A significant relationship between BODE scores and depression scores on the CES-D has been demonstrated ( $\rho = 0.35, p < .001$ ). Patients with higher BODE scores are more likely to be depressed (OR 4.0, 1.5-10.6,  $p = .007$ ). Depression and GOLD stage were not correlated (OR

1.2, 0.5-2.7,  $p = .9$ ). In fact, both anxiety and depression correlated more closely with BODE stage ( $K\tau = 0.20, p = .001$ ;  $K\tau = 0.41, p < .001$ ) than FEV1/GOLD ( $K\tau = -0.13, p = .037$ ;  $K\tau = -0.28, p < .001$ ). The mean anxiety scores on the Hospital Anxiety and Depression scale (HAD-A) (Zigmond & Snaith, 1983) for BODE Stage 1-IV were 6.3, 7.7, 9.5 and 8.5 respectively,  $p < .0001$ . Mean depression scores in the HAD-D (Bjelland et al., 2002) for stages were 4.6, 7.2, 9.7 and 10.9 respectively,  $p < .0001$  (Funk, Kirchheiner, Burghuber, & Hart, 2009). These findings indicate that overall disease impact constitutes a greater psychological burden than disease severity alone.

There is currently no cure for this progressive, debilitating disease. Treatment is aimed at slowing the rate of disease progression, slowing lung decline, improving overall functional ability, minimizing symptoms and maintaining HRQOL (Rabe et al., 2007). This is accomplished through an overall disease management plan with a focus on prevention and early treatment of exacerbations (Bourbeau & van der Palen, 2009; Rabe et al., 2007), the major precipitator of overall decline (Donaldson & Wedzicha, 2006; Donaldson, Seemungal, Bhowmik, & Wedzicha, 2002; Seemungal et al., 1998) and mortality (Soler-Cataluna, Martinez-Garcia, Sanchez, Salcedo, & Navarro, 2005) in patients with COPD.

### **COPD exacerbation manifestations, diagnosis and classification**

Acute exacerbations are relevant events in COPD disease progression, and are related to morbidity, mortality (Donaldson et al., 2002; Donaldson et al., 2006; Seemungal et al., 2000) and poorer HRQL (Miravitles et al., 2004; Seemungal et al., 1998). They are also a major cause of health care utilization and cost (Yu-Isenberg et al., 2005).

As COPD is heterogeneous in its pattern and presentation, so too is COPD exacerbation. Individuals experience a wide range of symptoms during their exacerbation, including increased

dyspnea, increased cough, increased sputum and/or purulence, wheeze, chest tightness and fever. Non-specific symptoms such as general malaise, fatigue, may also be present (Seemungal et al., 1998). The pattern of symptoms exhibited with each exacerbation is variable among individuals, but consistent within individuals (Kessler et al., 2006). An individual's unique exacerbation pattern is likely influenced by the characteristics of their underlying disease pathology as well as the infectious/inflammatory trigger. Subjective symptoms are accompanied by an objectively measured increase in airway obstruction (reduced FEV1) (Seemungal et al., 2000), however FEV1 change alone is not diagnostic of exacerbation.

Bacteria and /or viral infections trigger 50-70% of exacerbations, but non-infectious factors have also been implicated. Moreover, in 30% of exacerbations, no cause has been identified (Balcells et al., 2009). Viral upper respiratory infections (URI) are a frequent exacerbation precipitant (50%) and are associated with more severe exacerbations, hospitalizations, and longer recoveries (Wedzicha, 2004). Bacterial infection accounts for 30-50% of COPD exacerbations, and are more frequently indicated in individuals with FEV1 % predicted < 50%, or severe disease (Sethi, Evans, Grant, & Murphy, 2002). Increased air temperature, stress and air pollution play a minor role in COPD exacerbation, and often are a co-contributor (Mallia & Johnston, 2005).

Increased breathlessness is the primary symptom reported by individuals experiencing an acute exacerbation, and may or may not be accompanied by increased cough and sputum, change in sputum purulence, wheezing, chest tightness, and fever as well as non-pulmonary complaints such as fatigue, malaise, insomnia, depression (Rabe et al., 2007). Although many describe one or more major Anthonisen criteria symptoms, many individuals reported minor symptoms such as fatigue, sore throat, cold symptoms and mood disturbance. For example, in the Seemungal et



al. (2000) study which identified 504 exacerbations in a population of 101 subjects, 8 % were associated with three major symptoms, 37% with two major symptoms and 55% of exacerbations were signaled by minor symptoms. Patients and practitioners alike need to be more aware of the possibility of non-hallmark respiratory symptoms being an indicator of exacerbation onset in order to more effectively intervene in a timely fashion (Rabe et al., 2007). Table 5 outlines exacerbation symptoms reported by subjects in the cited studies. The symptoms represent a worsening of their daily symptoms, which are unique to their individual disease component, as well as characteristics of the exacerbation trigger, such as bacterial or viral infectious agents. A comparison of the symptoms listed on Table 2 and Table 5 will highlight the reason many individuals with COPD have difficulty recognizing exacerbations of their disease, as many of the listed symptoms are simply an increase in intensity of usual daily symptoms, or those of the common cold.

**Table 5**

*COPD Exacerbation Symptoms*

Study	Purpose	Sample	Study method	Exacerbation symptoms increased or new onset
Adams et al. (2006) Multinational	Uncover patient perspective on COPD exacerbation	23 subjects 16M/7F Mod-severe mean age 67.7  median yearly exacerbation rate 3.0 (self-report)	Grounded theory	breathing difficulty sputum changes cough (increased) coryzal symptoms wheezing anorexia pain dizziness fatigue, weakness, malaise, sweating
Bourbeau et al. (2007) Canada	Impact of early identification of AE on health status	421 subjects M239/ FEV1/FVC 52% mean age 66  mean yearly rate exacerbation 1.6	Prospective cohort- 2 year	increased cough (69%) dyspnea (65%) sputum color (41%) sputum amount (61%) wheeze chest tightness cold symptoms sore throat

Study	Purpose	Sample	Study method	Exacerbation symptoms increased or new onset
				All had worsening of 1 Anthonisen symptom and minor symptom
Costi et al. (2006) Canada	Determine how COPD patients describe their exacerbation experience.	32 subjects 18M/14F FEV1 35% mean age 68	Qualitative description	difficulty breathing (84%), fatigue (81%) cold symptoms (59%) sputum color change (53%) increased sputum (47%) cough (44%) mood disturbance (44%) chest tightness  Triggers: environment (47%) infection (31%) excess activity (25%) emotional factors (16%) change in medications (9%)  Most patients ≥ 1 major Anthonisen symptom Many- fatigue, cold symptoms, mood disturbance
Donaldson et al. (2003) UK	Changes in exacerbation severity/frequency	132 subjects 91M FEV 1 38.4% mean age 68.4  (1111 exacerbations) 54% unreported  median yearly exacerbation rate 2.53	Longitudinal 5 years	dyspnea (60%) sputum purulence (17%) sputum volume (34%) cold symptoms (31%) wheeze (38%) sore throat (13%) cough (30%)
Hurst et al. (2009) UK	Temporal clustering of exacerbations	297 subjects 191M/106F FEV 1 45.4%  (2189 exacerbations)  median yearly exacerbation rate 1.97	Prospective cohort- 12 years	Symptoms for isolated, initial and recurrent events  dyspnea (67- 73%) sputum purulence (29-31%) sputum volume (47-51%) wheeze (37-33%) cold symptoms (37%, 31, 27%) sore throat (17%, 13%, 11%) cough (40%, 31%, 31%)
Kessler et al. (2006) Europe	Patient understanding, detection, experience of	125 subjects 82M/43F FEV1 50% mean age 66.6	Qualitative description	dyspnea (38.4%) fatigue (10.4%) URI (9.6%) cough (8.8%)

Study	Purpose	Sample	Study method	Exacerbation symptoms increased or new onset
	AECOPD	mean yearly rate exacerbation:4.6		pain (8%)
Langsetmo et al. (2008) Canada	Underreporting of exacerbations	421 subjects 59% M FEV1 46% mean age 66.5  (486 exacerbations) 68% unreported  mean yearly rate exacerbation 2.7	Secondary analysis	dyspnea (72%) sputum amount (42%) sputum color (21%)
Miravittles et al. (2007) Europe	Identify patient perceptions of AE and treatment expectations	1107 subjects 39% male 51% > 51 yrs old  80% ≥ 1 exacerbation/yr	Telephone survey	dyspnea (78%) cough (71%) mucus color (71%) SOBOE (49%) fatigue (48%) wheezing (47%) URI (45%) chest tightness (42%)
O'Reilly et al. (2006) UK	Incidence and burden of AE	309 subjects 56% M FEV1 50%  mean yearly rate exacerbation: 2.3 sx-based 2.8 event-based 33% > 3/yr	Prospective cohort-1 year	dyspnea (75%) sputum (49%) Fev1 < 50% (39%) Fev1 > 50%  minor symptoms: 56% Fev1 > 50% 39% Fev1 > 50%
Parker et al. (2005) Canada	Physiologic changes during AE symptom recovery	20 subjects M7/F13 FEV1 40%  exacerbations 20		dyspnea (100%) cough (80%) sputum (70%) sputum color (65%)
Russell et al. (1998) Europe	Explanatory model of hospitalization	30 subjects 30M FEV1 < 41% mean age 67	Qualitative description	Dyspnea chest pain, sleep difficulties cough fatigue nausea malaise syncope
Seemungal et al. (2000)	Describe time course and characteristics of	101subjects M73/F28 FEV1 42%	Prospective cohort-London 1995-1998	Dyspnea (64%), increased sputum (26%), sputum purulence (42%)

Study	Purpose	Sample	Study method	Exacerbation symptoms increased or new onset
UK	exacerbation	mean age 67  (504 exacerbations) 50% unreported  mean yearly rate exacerbation: 2.4		cold symptoms (35%) wheeze (35%) sore throat (12%) cough (20%)  37% associated with 2 major symptoms 8% had 3 major symptoms
Wilkinson et al. (2004)  (UK)	Determine effect of early treatment on exacerbation outcomes	128 subjects 128M FEV1/FVC 43% mean age 67.3  (1099 exacerbations) 60% reported  median exacerbation rate 2.51/year  Delay: median 3.69 days	Prospective cohort UK (1996-2002)	Dyspnea (65.7%) sputum purulence (26.6%), sputum volume (41.3%) cold symptoms (29.1%) cough (30.7%) increased wheeze (31.7%) sore throat (13%)

Since there is no single diagnostic symptom or group of symptoms, no definitive sign (Celli, MacNee et al., 2004; Pauwels et al., 2004; Seemungal, 1998) and no serologic markers for COPD exacerbation (Donaldson & Wedzicha, 2006; Pauwels et al., 2004), diagnostic criteria are based on several working definitions developed by researchers for the purpose of their interventional studies, or by international panels of experts trying to develop a consistent definition (Pauwels et al., 2004). Anthonisen et al. (1987) put forth the classic definition, based on patient symptomology, which is used by many practitioners and researchers today (Table 6) This definition has been modified (modified Anthonisen criteria) to include more discrete criteria and terms such as: the patient experiences two or more of three major symptoms for two consecutive days (Seemungal et al., 1998).

**Table 6**

## Anthonisen Exacerbation Typology

Type	Definition
Type 1 (major symptoms)	The occurrence of increased dyspnea, sputum volume and increased sputum purulence
Type 2	Two Type 1 (major) symptoms present
Type 3	One Type 1 (major) symptom in addition to at least one of the following (minor) symptoms: upper respiratory infection in past 5 days, fever, increased wheezing or cough, 20% increase in respiratory or heart rate
Modified Anthonisen Criteria	For at least 2 consecutive days, either two or more of three major (Type I) symptoms or any one major symptom together with a minor (Type 3) symptom

More recently, an international work group of respiratory physicians developed the following consensus definition, which was presented at the Thomas L. Petty 42<sup>nd</sup> Annual Aspen Lung Conference:

A sustained worsening of the patient's condition, from the stable state and beyond normal day-day variations, that is acute in onset and necessitates a change in regular medication in a patient with underlying COPD (Rodriguez-Roisin, 2000, p 399S).

The purpose of developing a standardized definition was to guide patient treatment seeking decisions and physician intervention decisions. It would also standardize clinical trial definitions, allowing for results to be evaluated and compared. This operational definition has proved problematic to some researchers due to measurement issues as well as the vagueness and subjectiveness of the terms: sustained worsening and change from stable state (Pauwels et al., 2004).

Researchers further categorized exacerbations in terms of clinical presentation (symptom-based) (Anthonisen et al., 1987) and/or health care resource utilization (event-based) (Rodriguez-Roisin, 2005). Symptom-based definitions rely on worsening symptoms, primarily those described in the Anthonisen Type 1 definition. However, not every individual with COPD

experiences these three specific symptoms in their exacerbation pattern, making it problematic (Pauwels et al., 2004). A recent approach towards helping patients to identify exacerbations using daily diary card recording is based on the symptom-based definition. Patients monitor changes in their unique daily symptoms and the presentation of any new onset symptoms that may indicate impending exacerbation (Donaldson et al., 2005; Hurst et al., 2009; Langsetmo et al., 2008; O'Reilly, Williams, Holt, & Rice, 2006; Seemungal et al., 1998; Seemungal et al., 2000; Wilkinson et al., 2004).

Event-based definitions of exacerbations are not concerned with symptom presentation, but a condition change that is significant enough to warrant a change in treatment and possibly hospitalization. This definition is frequently used in clinical trials as it is treatment focused (Pauwels et al., 2004). Unfortunately, for the purpose of research, event-based definitions do not capture unreported exacerbations (Seemungal et al., 2000). This controversy is a concern when comparing studies, and/or outcomes related to treatment success (Pauwels et al., 2004).

Annual exacerbation rates vary from as few as one (Caverley et al., 2005) to as many as five (Kessler et al. 2006). Lower rates are typically associated with studies using an event-based definition of exacerbation. This was supported in the reviewed studies, with reported symptom-based exacerbation rates of 2.3-2.7 (Donaldson et al., 2003; Langsetmo et al., 2008; O'Reilly, et al., 2006; Seemungal et al., 1998; Wilkinson et al., 2004) and 4.6- 5.0 (Haughney et al., 2005; Kessler et al., 2006; Miravitles et al., 2007). Calverley et al. (2005) reported an annual exacerbation rate of 1.3 events per year using an event-based definition, and a rate of 2.4 events per year using a symptom-based definition with diary card analysis. The higher symptom-based rate includes unreported exacerbations identified upon reviewing daily symptom diary cards. These would have been missed using only an event-based definition. Lower annual exacerbation

rates (1.95) were also reported by Hutchinson et al. (2007) and Marin et al. (2009) who used an event-based definition in their studies.

Among these studies, upwards of 50% of unreported exacerbations were identified retrospectively from daily symptom diary cards (Calverley et al., 2005; Donaldson et al., 2003; Hutchinson et al., 2007; Seemungal et al., 1998; Seemungal et al., 2000). This represents missed opportunities for early treatment. Failure to report exacerbations and/or seek timely health care consult is associated with an increased risk of hospitalization ( $\rho = 0.21, p = .04$ ) (Seemungal, 2000). Wilkinson et al. (2004) state that early treatment of acute exacerbation is associated with reduced mortality, reduced risk of hospitalization, faster recovery, preserved lung function and better HRQOL. Individuals that did seek treatment earlier in the course of their exacerbation were noted to exhibit worsening dyspnea ( $-0.42, 95\% \text{ CI: } -0.76 \text{ to } -0.08, p = .016$ ), sputum purulence ( $-1.30, 95\% \text{ CI: } -1.60 \text{ to } -0.92, p = .001$ ) wheeze ( $-0.59, 95\% \text{ CI } -0.93 \text{ to } -0.25, p = .001$ ) or sore throat ( $-0.78, -1.23 \text{ to } -0.33, p = .001$ ).

The rate of hospitalization for reported exacerbation events ranged from 6% in three prospective cohort studies, (Donaldson et al., 2003; Hurst et al., 2009; Wilkinson et al., 2004) to 21% in an international survey (Miravitles et al., 2007). Of note is the smaller sample size (132, 297, 128 respectively) in the former studies compared to the larger sample size ( $N=1100$ ) in the Mirivitles et al. (2007) study. Since Mirivitles and colleagues (2007) conducted a survey study, information regarding disease severity was unavailable, and age was reported broadly as percent of subjects' age 51 or greater, making further comparison between studies difficult.

Physiologic recovery from exacerbation occurs 5-14 days after onset of the exacerbation (Haughney et al., 2005; Hurst et al., 2009; Kessler et al., 2006; Langsetmo et al., 2008; Miravitles et al., 2007; O'Reilly et al., 2006; Seemungal et al., 2000; Wilkinson et al., 2004).

The time course of recovery may be influenced by many factors, including exacerbation severity and symptom presentation. Wilkinson et al. (2004) reported that individuals with more severe symptoms had a longer exacerbation (2.68 days per symptom, 95% CI: 2.06-3.31,  $p < .001$ ) period. Seemungal et al. (2000) found that increased dyspnea and cold symptoms at exacerbation onset was significantly associated with longer recovery. Recovery was also found to take longer with recurrent exacerbations over time, with recovery time for FEV1 and symptoms to return to baseline increasing by nearly one-half day every year over time. Although Seemungal et al. (2000) demonstrated a median recovery rate of 6 and 7 days for pulmonary function and symptoms respectively, they also noted that only 75% of subjects had recovered to baseline at 5 weeks, and 7.1% of subjects were still not recovered at 91 days. Donaldson et al. (2003) and Kessler et al. (2006) reported that some subjects believed they never returned to baseline after their exacerbation event.

Hurst et al (2009) recently published findings that add new understanding of exacerbations, as events that cluster in time. In their sample of 297 patients with COPD they noted that individuals who experienced a recent exacerbation were at increased risk for another in the following 8-week period. A recurrent exacerbation, defined as an additional exacerbation event within 8 weeks of the previous, and after five symptom free days, occurred in 50% of subjects. Recurrent exacerbations contributed significantly to overall exacerbation frequency ( $\rho = 0.81$ ;  $p < .0001$ ), and occurred at a median yearly rate of 0.18 (IQR, 0.00-0.89) per individual. There was no difference in individual symptom presentation between initial and recurrent exacerbations, or in recovery time.



## **Burden of COPD exacerbations**

COPD exacerbations significantly impact the health status and HRQL of individuals, and worsen depression (Quint, Baghai-Ravary, Donaldson & Wedzicha, 1998). In a prospective cohort study with 169 subjects (Quint et al., 1998) the presence of clinical depression (CES-D score > 16) increased from 42% of the population at baseline to 60% of the population at the time of exacerbation. SGRQ scores were also independently associated with CES-D, and significantly worsened as CES-D score increased ( $r = .47, p < .001$ ). Each 2.4 unit increase in CES-D corresponded to a 4 unit change in SGRQ total score ( $r^2 = .03$ ), which is the unit measure that constitutes a minimum clinically significant difference. Individuals who spent less time outdoors following their exacerbation were also more significantly depressed ( $r = -.34, p < .001$ ) and experienced a worsening in SGRQ score ( $r = -.22, p = .03$ ) (Quint et al., 1998).

Spencer, Calverley, Burge & Jones (2004) found that frequent exacerbations were independently associated with worsening of baseline SGRQ total score ( $P < .0001$ ) and rapid deterioration of health status ( $p = .0003$ ). Health status, measured by SGRQ scores, deteriorated 2 units.yr<sup>-1</sup> (95% CI, 1.7-2.1,  $p = .004$ ) in individuals with no exacerbations, and 2.6 units.yr<sup>-1</sup> (95% CI, 2.4-2.8,  $p = .004$ ) in individuals who experienced exacerbations.

Whereas, exacerbations increase depression, it has also been shown to increase exacerbation risk. Jennings, DiGiovine, Obeid and Frank (2009) reported that depressed individuals were 2.8 times more likely to experience exacerbations than non-depressed individuals (95% CI, 1.1-7.3,  $p = .003$ ). In line with this association, the mental health (MH) score of the Medical Outcomes Study Health Survey- Short Form (SF-36) (Ware & Sherbourne, 1992) has also been used as a valid predictor of exacerbation risk (Jennings et al., 2009; Parshall,

Mapel, Rice, Williams, & O'Reilly, 2008). For every one-point change in MH score, exacerbation risk increases 12.6% (Jennings et al, 2009).

The BODE index (described earlier) is a sensitive measure used to assess the impact of exacerbations on individuals. Cote, Dordley and Celli (2007) studied the impact of acute exacerbation on BODE outcomes. A sample of 205 individuals with moderate-severe COPD was followed for 2 years. As expected, individuals with a history of COPD exacerbations had worse baseline finding than those individuals with COPD who did not have an exacerbation event (4.2 +/- 2.1 vs. 3.57 +/- 2.3 respectively,  $p < .03$ ). Patients who experienced an exacerbation showed a significant worsening in BODE index of 1.38 points during the event, and remained above baseline up to 2 years (0.8 and 1.1 at 1 and 2 years respectively) compared to the control group that demonstrated no change from baseline.

Deterioration in lung function is also associated with frequent exacerbations. Donaldson et al. (2002) demonstrated that individuals who experience  $> 2.92$  exacerbations a year (median 4.2) have a significant decrease in FEV1 of 40 ml/yr compared to those 32 ml/yr in individuals with no, or infrequent exacerbation (median 1.9). These individuals were also hospitalized more often, and for longer periods of time.

If not treated early, acute exacerbations result in significant physical and psychosocial decline that persists from 2 weeks to several months. Early health care consult and treatment of an acute exacerbation of COPD reduces exacerbation severity and associated negative physical and psychosocial consequences. However, as the studies have demonstrated, symptoms of exacerbation often go unrecognized contributing to a treatment delay and poorer outcomes.

## **Symptom recognition**

Symptom recognition and interpretation is complex in COPD, and involves an understanding of COPD, exacerbation, and relationship to disease severity (Wilkinson, 2004). There is a paucity of literature on symptom recognition in patients experiencing exacerbation of COPD. Of three articles indexed in Pub Med for the terms symptom recognition and COPD exacerbation, only one specifically addressed patient symptom recognition. The researchers in this study explored the influence of psychosocial factors on symptom recognition and disease self-management (Dowson, Town, Frampton & Mulder, 2004). A further search of Pub Med identified 15 studies specific to symptom recognition studies in the myocardial infarction (MI) population. However, an MI is an acute event, and factors associated with symptom recognition may not be the same for individuals with chronic disease. Symptom recognition in heart failure exacerbation is also scarce. Five studies regarding symptom recognition in heart failure were indexed in Pub Med (Hedemalm, Schaufelberger, & Ekman, 2008; Horowitz, Rein, & Leventhal, 2004; Jurgens, 2006; Jurgens, Hoke, Byrnes, & Riegel, 2009; Patel, Shafazand, Schaufelberger, & Ekman, 2007) and reviewed. Heart failure and COPD are common in chronicity, symptom ambiguity and variability, presence of defining hallmark symptoms, and physical, emotional and economic burden of acute exacerbations (Jurgens, 2006). Therefore, the heart failure literature, in addition to the COPD literature, was reviewed for insights into symptom recognition that might be extrapolated to the COPD population.

Symptoms are sensations that signal a change in health status to the individual. Appropriate treatment-seeking behavior in response to symptoms is dependent upon symptom recognition, interpretation and evaluation of health status change (O'Neill & Morrow, 2001) making detection of subtle changes in symptom intensity challenging (Meek, Lareau, &

Anderson, 2001). Symptom recognition encompasses perception and evaluation. Symptom perception is the conscious cognitive interpretation of somatic information gathered through the senses that is subsequently interpreted through evaluation processes. Although perception and evaluation are conceptually different, they are interdependent processes, where sensation is integrated with contextual meaning and interpretation (O'Neill, 2002). If sensations are new to the patient, or ambiguous, recognition and subsequent action responses will be inadequate (Jurgens, 2006).

Delay in seeking treatment for heart failure and COPD exacerbations may be related to poor symptom recognition of acute health status deterioration (Hedemalm et al., 2008; Horowitz et al., 2004; Insel, Meek & Leventhal, 2005; Jurgens, 2006). Many individuals with COPD are always aware of their breathing, and may have less perceptual sensitivity to subtle changes (Insel et al., 2005). This is particularly implicated in individuals with higher PaCO<sub>2</sub> levels (Dowson et al., 2004). Poor symptom recognition is also related to the chronicity of the conditions, daily presence of multiple symptoms and variability in intensity and frequency of symptoms that can sometimes be insidious (Carlson, Riegel, & Moser, 2001; Evangelista, Dracup & Doering, 2000; Insel et al., 2005; Jablonski, Gift & Cook, 2007; Main, 1983; Meek et al., 2001; Patel, Shafazand, Schaufelberger, & Ekman, 2007). In Hedemalm et al. (2007), a qualitative study (N=42) of symptom recognition in heart failure, 52% of subjects failed to recognize early warning signs of decompensation (exacerbation). Horowitz et al. (2004) reported that heart failure subjects (N=19) detected a change from baseline status, but failed to interpret them as a severe threat necessitating urgent health care consult. Patient's with COPD also need to understand there is a range of symptom intensity at baseline that constitute 'good days' and 'bad days'. It is also important for patients to recognize changes in symptom patterns that

distinguishes a ‘bad day’ from one that requires health care consult (Adams et al., 2006; Bourbeau & Nault, 2007). This includes associating non-respiratory symptoms with acute exacerbation (Costi, Brooks, & Goldstein, 2006).

In both COPD and heart failure, dyspnea and fatigue are prominent symptoms at baseline and during exacerbation (Barnett, 2005; Gift & Shepard, 1999; Jablonski et al., 2007; Jurgens, 2006), and interpreting a change that is significant is challenging due to the high level of daily variability (Carlson et al., 2001). Additionally, patients tend to normalize symptoms to contextual factors such as environment and fatigue, contributing to minimization of symptom threat (Posey, 2006). This is especially evident in COPD, where environmental factors and physical activity play heavily into the symptom experience. Dyspnea is especially ambiguous in COPD, as it is not specific to airway obstruction, but involves interplay of physiological and psychological factors (Reishtein, 2005). However, even in heart failure, perception of dyspnea change is difficult, with perception improving significantly as the duration of change becomes longer ( $r = .30$ ,  $p = .013$ ) (Jurgens, 2006). Wilkinson et al. (2004) call for further studies into mechanisms of symptom recognition in individuals with COPD to better inform how to improve reporting behavior during exacerbation and improve outcomes.

### **Prodromal symptom recognition**

Prodromal symptoms are subtle symptoms that present before the onset of an illness, and are often ignored (Seemungal et al., 2000). To date, no studies were found in which patient awareness of prodromal symptoms that precede COPD exacerbation was the specific research topic. However, the importance of prodromal symptom recognition in facilitating early treatment of COPD has been discussed (Langsetmo et al., 2008; Seemungal et al., 2000). The authors acknowledge the presence of a prodromal period of from one to seven days prior to

exacerbation onset. Seemungal et al. (2000) reported that during this period subjects experienced subtle changes in dyspnea, cold symptoms, sore throat and cough, without a significant decline in lung function measurement. However, on the day of exacerbation onset, subjects experienced a sharp increase in dyspnea (65%), sputum purulence (42%), cold symptoms (35%), wheeze (35%), sputum amount (26%), cough (20%) and sore throat (12%). Peak expiratory flow (PEF) measurements also declined by 8.6L/min at onset of exacerbation. Since intervention prior to this sharp decline can significantly alter outcomes, prodromal symptoms (dyspnea, cold symptoms, sore throat and cough) are particularly important to recognize and respond to in an attempt to avert exacerbation (Langsetmo et al., 2008).

### **Treatment Delay**

It has been well documented that 50% or more COPD exacerbations go unreported (Calverley et al., 2005; Donaldson et al., 2003; Hutchinson et al., 2007; Seemungal et al., 1998; Seemungal et al., 2000) and therefore are untreated, or treated late in the course of exacerbation, (Calverley et al., 2005). Individuals delayed seeking treatment from a median of 3.69 days (Wilkinson et al., 2004) to 7 days (Gruffyd-Jones et al. (2007), often waiting until symptoms were unbearable (Chandra, Tsai, Camargo, 2009; Russell et al., 1998). The reason for this delay is not clear. Individuals may not understand the disease course and importance of prompt health care consult and treatment (Rennard 2002, Wilkinson, 2004). Depression has also been implicated in treatment delay, as depressed individuals often lack the motivation to seek care during a change in health status (Donaldson & Wedzicha, 2006; Dowson et al., 2004). It is also not certain if unreported exacerbations are so mild as to be dismissed by patients as a normal day-to-day variation in their disease state (Donaldson & Wedzicha, 2006). It is known that patients who do not report exacerbations consequently have a poorer HRQOL. This is associated

with the prolonged recovery and physiologic impact of delaying treatment (Wilkinson et al, 2004). It is therefore imperative to understand the reason individuals delay seeking treatment, and intervene appropriately.

Although treatment delay was not the primary research question in the following COPD studies, many factors associated with delay were extrapolated. Situations and behaviors associated with delay included: poor provider relationship and/or communication (Adams et al., 2006; Schofield, Knussen & Tolson, 2006), lack of specific knowledge about COPD (Adams et al., 2006; Dowson et al., 2004), unawareness of symptoms of worsening state (Adams et al., 2006; Dowson et al., 2004; Schofield et al., 2006; Wilson et al., 2007), concern over family responsibilities (O'Neill, 2002), not wanting to bother health care providers (Gruffyd-Jones et al., 2007), fear of hospitalization (Gruffyd-Jones et al., 2007), lack of knowledge regarding when and where access to care (Gruffyd-Jones et al., 2007; O'Neill, 2002; Wilson et al., 2007), denial (Schofield, Knussen & Tolson, 2006), wait and see behavior (Schofield et al. 2006; Wilson et al., 2007) and co-morbid depression (deVoogd et al., 2009; Putnam-Casdorph & McCrone, 2009; Wilson et al., 2007).

The Asthma population shares some commonalities with the COPD population in symptomology and medication treatment, although asthma is more episodic in nature than COPD. Research findings regarding treatment-seeking delay in this population may have implications for the COPD population as well. Janson and Becker (1998) described treatment-seeking delay in a sample of 82 patients with asthma. Eighty-six percent of patients exhibited treatment-seeking delay, that was attributed to uncertainty (74%), not wanting to disrupt family (86.5%), minimization of symptoms (90%), having a previous bad experience with health care system (42%), fear of systemic corticosteroids (31%), a need to tough it out (46%), and

economic reasons (6%). In this sample, 74% of patients had three or more reasons for delay, and 16% experienced a “crisis” before seeking treatment. Thirteen patients, who did not delay in this study, reported delaying treatment in the past but now feared they would die if they did not seek timely health care consult. This was a result of the frightening near death experience they had during a previous exacerbation episode. Similar to Jason and Becker’s (1998) findings, fear of death has been expressed by individuals with COPD (Andenaes, Kalfoss, & Wahl, 2006).

Again, because of similarities between COPD and heart failure, the heart failure literature was examined to glean insight into delay in treatment seeking. In the heart failure studies the inability to recognize and address worsening symptoms, inappropriate perception of illness threat (Horowitz et al., 2004), taking a wait and see approach, and barriers to care were cited as reasons for delay in seeking treatment (Horowitz et al., 2004; Patel et al., 2007). Failure to recognize insidious symptoms of heart failure, and assess the seriousness of hallmark symptoms were also cited as causes of delay by the authors, stating 57% of subjects were uncertain as to the cause of their symptoms. Even experienced heart failure patients have difficulty recognizing subtle changes heralding worsening heart failure (Freidman & Quinn, 2008) and distinguishing between acute and chronic symptoms (Jurgens, 2006).

Treatment-seeking delay is a problem that impairs health status, and is prevalent in acute and chronic illnesses. In acute illness, unawareness of symptoms is a commonly reported feature of delay. However, in chronic diseases, treatment delay involves multiple, complicated factors, as noted above. Factors contributing to treatment delay in COPD need to be articulated so that prompt identification and treatment can be promoted, and health outcomes improved.



## Summary

A clear pattern of COPD symptoms, dominated by dyspnea and fatigue that varies in intensity from day to day has emerged from this review. The presence of fatigue is also associated with a decline in physical function (Adams et al. 2006), worsening dyspnea (Baghai-Ravary, 2009; Kinsman, 1983), depression and anxiety (Al-shair et al., 2009; Putnam-Casdorph, 2009) that lead to social isolation and poorer HRQOL (Cicutto, Brooks & Henderson, 2004). A constellation of exacerbations symptoms that present in a recurring, individualized pattern has also been highlighted. In one study, more than one-half of exacerbations manifested with ‘minor’ Anthonisen criteria symptoms (Seemungal et al., 2000). Although these symptoms can be subtle, and often ambiguous, some subjects were able to identify and quantify them using a daily symptom diary cards in many of the studies (Caverley et al., 2005; Donaldson et al., 2003; Seemungal et al., 2000). However, this recognition did not translate effectively into meaningful action. Fifty percent or more exacerbations, identified retrospectively from diary cards, went unreported and untreated, representing missed opportunities for timely treatment and improved disease outcomes (Caverley et al., 2005; Donaldson et al., 2003; Seemungal et al., 2000). This is especially critical in light of new understanding of exacerbations as events that cluster in time, with recurrent exacerbation occurring within 8 weeks of the initial event, with multiplicative negative consequences (Hurst et al., 2009).

Across studies, subjects consistently delayed treatment seeking, often resulting in costly hospitalizations. It is not understood why this delay occurs. It is possible that patients are not appropriately judging the seriousness of their symptoms, are not recognizing symptoms (or symptom patterns) as signs of exacerbation, or that psychological mechanisms are affecting judgments and impeding action. Since most of the physiologic, psychosocial and economic

burden of COPD is associated with acute exacerbation events, early recognition and treatment of acute exacerbations of COPD is an important management goal, and meeting this goal is predicated upon understanding how individuals with COPD recognize and respond to symptoms of exacerbation.

#### Purpose and specific aims

The purpose of this qualitative descriptive study was to explore the COPD exacerbation experience. The specific aims are to:

1. Explore awareness of prodromal symptoms in the days preceding an acute exacerbation of COPD.
2. Describe recognition of symptom patterns associated with acute exacerbations.
3. Identify dimensions of illness representation (identity, time-line, cause, consequence, controllability) in individual descriptions of treatment-seeking delay during exacerbation of COPD.

## Chapter 2

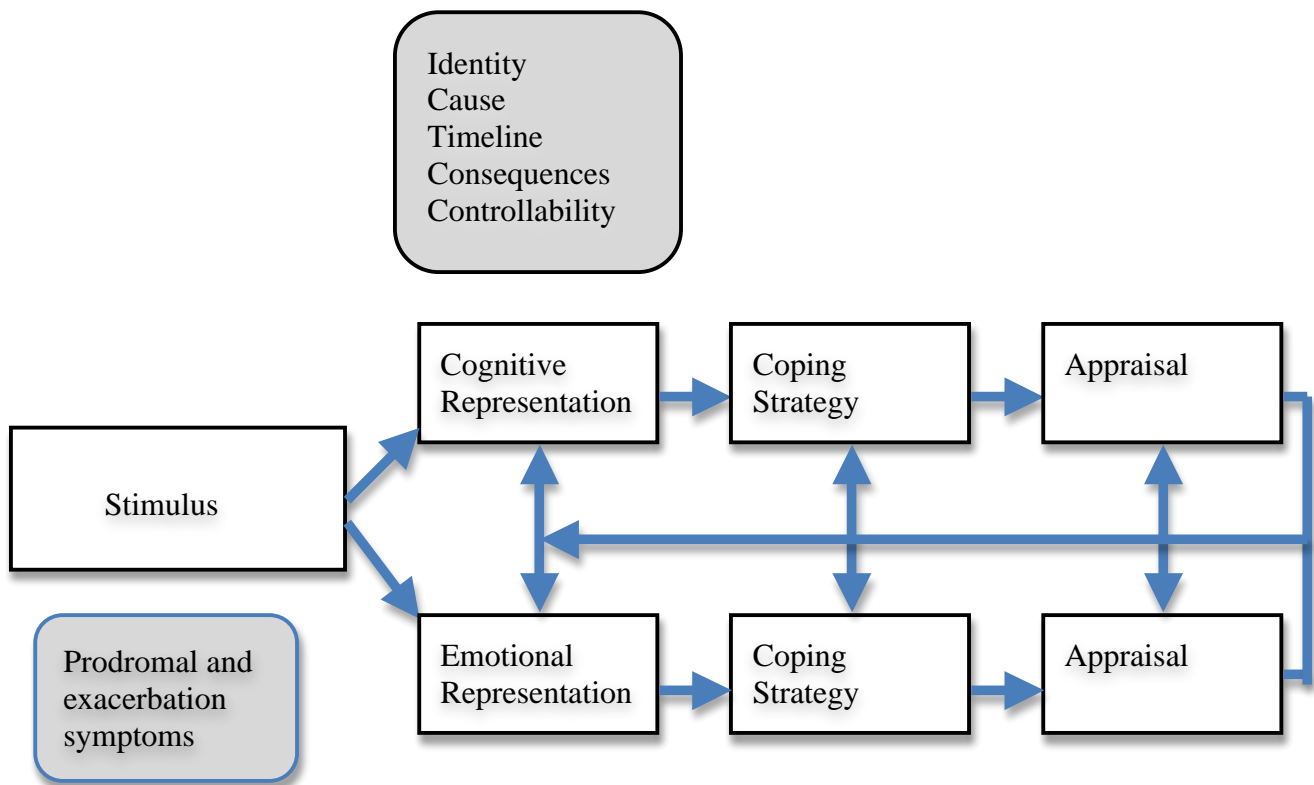
### **Theoretical Framework**

This chapter describes the Common Sense Model (CSM) of illness representation (Leventhal, Meyer & Nerenz, 1980) that undergirded this study (Figure 1) The CSM is based on the parallel response (process) model (Leventhal, 1970) and self-regulatory information processing theory (Leventhal, 1971) and is the result of an extended program of research by Leventhal and colleagues (Johnson & Leventhal, 1974; Leventhal, 1970; Leventhal, 1971; Leventhal, Meyer & Nerenz, 1980; Nerenz & Leventhal, 1983). The Common-Sense Model is sometimes referred to as the Illness Perception Model, Illness Representation Model, Self-regulatory Model and the Parallel Process Model (Hale, Treharne & Kitas, 2007). The name changes reflect new evidence and insights into the mechanisms that underlie responses to health threats (Leventhal, 2011).

Although there are other general self-regulation models that are similar in their use of a systematic process to modulate behavior, such as the Social Learning Model (Bandura, 1969), Health Belief Model (Rosenstock, 1966), Theory of Reasoned Action, (Fishbein & Ajzen, 1975), Self-Efficacy (Bandura, 1982), and The Self Regulation Model, (Carver & Scheier, 1981), the unique properties and assumptions of the CSM sets it apart from the others. In this model, cognitive representations, or patient beliefs and expectations about a health threat or illness, are the central component of the theory. Illness representations have five distinct attributes: identity, timeline, consequences, cause and control. As an illness representation is formulated and processed through parallel cognitive and emotional processes, a subsequent health behavior is engaged (Brownlee, Leventhal & Leventhal, 2000, Diefenbach & Leventhal, 1996). Because of the CSM's core construct of an illness representation with five distinct attributes, its parallel

processing of cognitive and emotional aspects of the illness threat, and focus on illness behavior, it is a good fit to guide this study. Individuals experiencing acute exacerbation of COPD are challenged with distinguishing new or worsened symptoms from their day-to-day symptom experience, accurately representing the health threat as an exacerbation and taking appropriate action. This is complicated by emotional processing of symptoms using prior experience memories, which may interfere with accurate illness representation and/or coping (action).

The CSM is an information-processing model that describes the processes individuals use to represent their illness threat and take action, in the form of self-regulating behaviors. Within the context of the common-sense model, self-regulation refers to the regulation of the physical self and available resources in order to achieve identified goals. Actions taken in the process of regulation depend on each specific threat to health, resources available to the individual and the social context in which the individual is situated (Leventhal, Brissette & Leventhal, 2003). The central assumption of the CSM is that information processing involves three stages: representation, coping and appraisal. In the representation stage, individuals organize, analyze and interpret information and provide meaning. Based on the specific representation that is formulated, a response is initiated during the coping stage. In the final appraisal stage, coping responses are evaluated for effectiveness (Keller, Ward, & Baumann, 1989). Individuals may process the same illness differently with subsequent occurrences, cope accordingly and appraise the event using different criteria each time (Leventhal & Cameron, 1987). This dynamic processing and appraisal also distinguishes the CSM from the other self-regulatory models.



*Figure 1.* The commonsense model of illness representation (Diefenbach & Leventhal, 1996) as applied to acute exacerbation of COPD. Model was adapted and used with permission from Dr. Howard Leventhal. The non-shaded boxes define the attributes of cognitive illness representation, and the stimulus for cognitive and emotional processing in this study. The light shaded concepts will be explored in this study.

The CSM model also proposes that individuals use parallel cognitive (objective, controlled) and emotional (subjective, automatic) processes to generate “commonsense” perceptions of health threats that lead to the formation of an illness representation (Leventhal, Meyer & Nerenz, 1980, Leventhal, Meyer & Steele, 1984). These processes are independent, but interact and may facilitate or interfere with treatment seeking (Leventhal, Meyer & Steele, 1984). As an exemplar, consistent with the proposed study, an individual with COPD might experience an increase in cough and sputum production and remember having similar symptom with a previous “exacerbation”, and thus form a cognitive illness representation of acute COPD

exacerbation. Additionally, a parallel emotional reaction to the illness threat, one that involves the physician prescribing “those terrible steroid medications” may be formed.

Illness representations provide the impetus for subsequent coping actions (adaptive or maladaptive) including treatment-seeking behaviors (Leventhal, Meyer & Nerenz, 1980). If the illness threat is perceived as low, or involves undesirable treatment, then the representation may not lead to appropriate coping or action. However if the symptom is perceived as serious, socially isolating or difficult to manage, then the individual is more likely to seek medical attention (Cameron & Leventhal, 1993). Continuing with the prior exemplar, the individual may be directed by the cognitive representation to seek health care provider consult, or be influenced by the emotional process and take a wait and see approach in an attempt to avoid steroids.

During the final stage of the process, outcomes are appraised (reappraised) and may initiate a revision of the initial representation, coping strategy, or emotional response (Leventhal, Benyamini, Brownlee et al., 1997; Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984). In the ongoing exemplar, this might include worsening of symptoms to an uncomfortable level, a revision of the cognitive and emotional representation to “serious” exacerbation, and possibility of death, and a new coping strategy that includes treatment seeking.

As illustrated above, the illness representation stage of information processing involves cognitive and emotional processes. There are five domains (attributes of an illness representation) associated with the cognitive process: identity, consequences, causes, timeline (Leventhal, Meyer & Nerenz, 1980) and controllability (Lau & Hartman, 1983).

### **Identity**

Identity, the identification of disease/illness threat, is the core domain. It involves abstract cognition (vulnerability) and concrete experiences (symptoms) to produce an illness

label (Leventhal, Meyer & Nerenz, 1980, Meyer, Leventhal & Guttman, 1985). Individual differences in the extent to which individuals are sensitive and aware of bodily sensations will also have a strong impact on this domain (Keller et al., 1989). Appropriate identification and labeling of a symptom or illness is contingent on having knowledge (education or experience), intact symptom awareness, and the ability to perceive the seriousness of the event. In the proposed study of individuals with COPD who experience multiple symptoms of varying intensity on a daily basis, it may be more difficult for them to differentiate acute illness-related symptoms from fluctuations in chronic symptoms. Additionally, biochemical alterations related to chronic hypoxemia and hypercarbia may decrease perceptual abilities in these individuals. These deficits may contribute to failure to identify acute illness and/or inaccurate representation, and subsequent treatment delay.

### **Consequences**

Consequences refer to the perceived physical, emotional, social and economic impact of the disease/illness threat. It is influenced by the severity of the specific illness event and beliefs about the impact the illness will have on daily life and functioning (Leventhal, Meyer & Nerenz, 1980). For the COPD patient experiencing an acute exacerbation, undesired medication side effects, hospitalization and fear of death are a few common consequences that influence illness representation.

### **Cause**

The perceived cause of a disease/illness can be multifactorial, and includes infection, stress, environment, emotions and heredity. Causes are further categorized into internal and external factors. Internal factors include personal behaviors that the individual believes caused their health threat. External factors include environmental factors, as well as the individual's

belief system, such as fate (Leventhal, Meyer & Nerenz, 1980). For a patient with COPD, continued smoking and overexertion are factors that may inhibit treatment seeking as a coping behavior due to self-incrimination over their “forbidden” lifestyle behaviors.

### **Timeline**

The perceived timeframe for the onset and duration of the disease/illness constitutes the timeline. It is often based on experience and abstract knowledge (Leventhal et al., 2003). For the individual with a chronic disease like COPD, the timeline is naturally long, and these individuals often employ a “tough it out” strategy even during acute illness episodes.

### **Controllability/Cure**

Lau and Hartman (1983) added this fifth attribute. The individual’s perceived ability to prevent, control or cure an illness or disease influences their perception of disease controllability and how one goes about recovery (Lau & Hartman, 1983). Again, the chronic, debilitating nature of COPD can negatively impact the individual’s perception of control over their disease and/or acute flare ups.

### **Emotional Processes**

Emotional processes also affect illness representation, and can directly affect the representation as well as coping behaviors. Emotional responses can alter perception of symptom severity as well as produce additional symptoms not otherwise included in an illness presentation. Emotional responses may also negatively affect cognitive processing of the illness representation, resulting in ineffective coping responses (Leventhal, Brissette & Leventhal, 2003). Illness representations are also influenced by the individual’s existing knowledge base and information sources. These knowledge and information sources include prior experiences with illness, media sources, health provider resources, social contacts and cultural beliefs



(Leventhal & Nerenz, 1985). If an individual with COPD typically has moderate to severe exacerbations that require undesirable hospitalizations, then he might inaccurately represent a mild episode as a cold and self treat rather than seek health care consult. This represents a missed opportunity for early treatment of exacerbation and preservation of vital lung function.

Three patterns of illness representations, with interrelated attributes, have been proposed by Leventhal, Nerenz and Steele (1984) based on the identity, consequence, timeline and cause attributes: a short term acute episode model that culminates with cure, a cyclic model of illness exacerbation and remission, and a chronic model involving long-term symptom monitoring and care. For the individual with COPD, the chronic model best fits their disease trajectory as their disease never goes into remission, but fluctuates from an individualized baseline level of stability to acute instability associated with each acute exacerbation.

### **Use of the Common Sense Model in Research**

The common-sense model has been used in many qualitative and quantitative research studies to describe how individuals derive illness representations from symptoms, and how illness representations affect care seeking and management. Findings in these studies have supported its usefulness in understanding health behaviors and predicting health outcomes. The CSM also undergirded the development of the Illness Perception Questionnaire (IPQ), a psychometrically sound scale that provides a quantitative assessment of the cognitive and emotional components of the CSM of illness representation (Weinman, Petrie, Moss-Morris & Horne, 1996). The following is a literature review of research (see Table 7) conducted in the last 2 decades in which the CSM was used to better understand symptom recognition, coping actions, treatment adherence and/or care seeking. Because of the paucity of literature available in which the CSM was used with the COPD population, research on non-COPD pulmonary (asthma) and

cardiac (heart failure) populations was included. These chronic illnesses are similar to COPD in that they have a chronic illness trajectory that is often punctuated with cyclic episodes of acute illness (exacerbations). Additionally, individuals with these illnesses often experience similar daily symptoms (dyspnea, fatigue) that fluctuate in intensity making exacerbation symptom recognition challenging.

Table 7

Studies that used CSM

Author, Date	Title	Sample Method	Assessment Tool Based on CSM	Results
Quantitative Studies				
Albert & Zeller (2009)	Depressed patients understand heart failure (HF) prognosis but not how to control it	N=219	Survey of illness beliefs in HF (Albert & Zeller, 2007)  Mean score $\geq 3$ indicates accurate illness beliefs	Mean illness belief score = 2.99 (slightly inaccurate beliefs)  Consequence attributes significantly more accurate in individuals with higher levels of depression (mean 3.31, $p = .001$ )  Consequences, timeline, identity, control illness beliefs predictive of depression $r = .22$ , $p = .001$ ; $r = .17$ , $p < .01$ ; $r = .13$ , $p < .05$ ; $r = .12$ , $p < .05$ respectively.
Howard, Hallas, Wray & Carby (2009)	Relationship between illness perceptions and panic in COPD	N=59 Cross-sectional	Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al, 2002)	Beliefs relating to illness identity, timeline, consequences, emotional representation differed in panic (maladaptive) vs. non-panic (adaptive) emotional responses to COPD symptoms  Panickers had stronger identity beliefs ( $t = 2.734$ , $p = .01$ ), longer time-line expectation ( $t = 2.026$ , $p < .05$ ), perceived more severe consequences ( $t = -2.373$ , $p < .05$ ), and had greater emotional representation ( $t = -2.093$ , $p < .05$ ) than non-panickers  Correlation between panic severity and consequences (.768, $p = .000$ ); emotional representation (.750, $p = .000$ ).

Author, Date	Title	Sample Method	Assessment Tool Based on CSM	Results
Jurgens, Hoke, Byrnes & Riegel (2009)	Why do elders delay responding to heart failure symptoms?	N= 77 Mixed-methods)	IPQ	Poor symptom recognition due to subtlety/ambiguity of early warning signs to contribute to treatment delay > 3 days in 50% subjects  56% did not know symptoms of HF (identity) or perceive seriousness (consequences) 80% waited for symptoms to go away 54% believed had no control over symptoms (controllability) 50% reluctant to trouble anyone  Lack of emotional response to early symptoms (anxiety or fear) surprising, compromised action
Scharloo, Kaptein, Schlosser, Pouwels, Bel, Rabe & Wouters (2007)	Illness perceptions and QOL in patients with COPD	N=171 Correlational	IPQ-R	Illness perceptions related to QOL Identity (-.45, $p < .001$ ) Consequences (-.40, $p < .001$ ) emotional representation (-.60, $p < .001$ ) inversely correlated with QOL (QoLRIQ)*  Less belief in chronic timeline associated with improved QOL (-.44, $p < .001$ )(SF-36)**
Cherrington, Lawson & Clark (2006)	Illness representations of patients with systolic heart failure	N=22 Descriptive	IPQ-R Subscale means measured (+/-) from neutral point (3)	Subjects perceived HF as cyclic (3.5), chronic (4.1), with serious consequences (3.9) and some controllability (4.2)
Jessop & Rutter (2003)	Adherence to asthma medication: the role of illness representations	N=737 Exploratory	Beliefs About Asthma Questionnaire (Jessop & Rutter 1999) (based on IPQ)	Illness representations that predicted adherence in multiple regression analysis included illness label $t(227) = 2.53, p < .05$ , external cause $t(227) = 2.04, p < 0.05$ , and cure-control $t(227) = 2.01, p < .05$ .
Horne & Weinman (2002)	Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in non-adherence to preventer medication	N=100 Cross-sectional	IPQ Beliefs about Medicine Questionnaire (BMQ) (Horne et al., 1999)	Non-adherence associated with doubts about medication necessity ( $r = .32, p < .01$ ), concerns about side effects  Positive inter-correlations between medication necessity beliefs and timeline ( $r = .30, p < .01$ ), consequences ( $r = .30, p < .01$ ) and adherence

Author, Date	Title	Sample Method	Assessment Tool Based on CSM	Results
Byer & Myers (2000)	Psychological correlates of adherence to medication in asthma (2000)	N=64 Correlational	IPQ, BMQ	Increased self-reported adherence correlated with illness perception domains of identity & timeline (long, chronic) ( $r = .40$ , $p < .01$ ; $r = .30$ , $p < .05$ )
Scharloo, Kapstein, Weinman, Hazes, Willems, Bergman, Rooijmans 98)	Illness perceptions, coping and functioning in patients with RA, COPD and psoriasis	N= 244 COPD n=80 Cross-sectional	IPQ	COPD- in stepwise regression, passive coping explained 8% variance on physical function, (MOS)** small but significant finding. Identity explained 13% variance on role functioning, 18% variance on social functioning  Strong illness identity, passive coping, long illness duration, strong consequences belief and low FEV1 correlated with worse outcomes

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Qualitative studies

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Horowitz, Rein & Leventhal (2004)	A story of maladies, misconceptions and mishaps: effective management of heart failure	N=19 GT	Interview and analysis guided by CSM	Patient's low perception of HF symptoms and poor understanding of illness affect behavior. Patients understood HF as acute event > chronic event- so poor routine management, and preventative +/- minimizing behaviors during exacerbation. Themes: 1. Inadequate information about CHF (impacts all domains of representation) 2. Insufficient tools to prevent, recognize, act on exacerbations in early stages 3. Barriers to care
O'Neill (2002)	Illness representation and coping of women with COPD: a pilot study	N=21 Qualitative description	Interview and analysis guided by CSM	Causes and consequences attributes most fully elucidated in illness representations. Subjects has correct label for identity (n=20) and a vague timeline representation. Coping strategies were triggered by beliefs about their symptoms, prior experiences with symptoms and techniques learned in rehab

\*Quality of Life for Respiratory Illness Questionnaire (Maille, Konig, Zwinderman, Willems, Dijkman & Kaptein, 1997)

\*\*Medical Outcome Survey (MOS) SF-36 (Ware & Sherbourne, 1992)

The cited qualitative studies (Horowitz et al., 2004; O'Neill, 2002) used the CSM to inform interview guide development as well as data analysis. O'Neill (2002) tailored interview questions to specifically address each of the five cognitive domains to describe how individuals represent and cope with COPD. Inductive content analysis revealed a rich description of patient's understanding and living with COPD. Findings included a clear identification (label) of COPD, a rich representation of the cause (smoking, occupational exposure), well elucidated consequences, and coping strategies that were clearly linked to patient beliefs and experiences. Horowitz et al. (2004) compared themes generated from interview data to the CSM framework to better understand how perceptions and knowledge of heart failure guided action and coping. Clearly the cognitive domains of identity, consequences and timeline influenced self-management and treatment seeking behavior. Inaccurate or incomplete illness identity was linked to decreased knowledge and understanding of heart failure with subsequent poor recognition and management of their chronic illness and/or acute exacerbations. This was compounded by an inaccurate representation of heart failure as an acute illness rather than a chronic illness punctuated by episodes of acute exacerbations. In these studies, the CSM was beneficial in describing factors that can impede self-management of chronic illness (Horowitz et al., 2004; O'Neill, 2002) and symptom recognition and treatment seeking during acute exacerbations (Horowitz et al., 2004).

The reviewed quantitative studies (Albert & Zeller, 2009; Byer & Myers, 2000; Cherrington, Lawson & Clark, 2006; Horne & Weinman, 2002; Howard et al., 2009; Jessop & Rutter, 2003; Jurgens et al. , 2009; Scharloo et al., 2007; Scharloo et al., 1998) used a variety of scales (developed based on the CSM framework) to measure cognitive and emotional components of the CSM and/or to explore relationships between the domains of illness

representation and QOL, depression, medication adherence, coping and functioning, and treatment delay. Studies in COPD will be reviewed first, followed by asthma and then heart failure.

Scharloo et al. (1998) investigated the association of illness perceptions and coping with daily functioning (1998) in individuals with COPD, rheumatoid arthritis and psoriasis. Illness perceptions were assessed using the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, Horne, 1996). Coping and daily activities of living were also quantified utilizing disease appropriate scales. In COPD patients, FEV1 was also measured to determine disease severity. Multiple regression analysis was conducted to examine the influence of illness perception domains and coping on daily functioning. Findings revealed that coping did not contribute to variance on any outcome measure in COPD. However the illness representation domain identity (more symptoms) explained 13% of variance in role functioning ( $R^2 = .30$ ,  $F = 8.82$ ,  $p = .001$ ) and 18% of variance in social functioning ( $R^2 = .18$ ,  $F = 6.21$ ,  $p < .01$ ). Nearly a decade later a revised version of the IPQ (Moss-Morris et al, 2002) was used to examine the relationship between illness perception and QOL (Scharloo et al., 2007). This study revealed that the cognitive domains of identity ( $r = -.45$ ,  $p < .001$ ) as well as consequences ( $r = -.40$ ,  $p < .001$ ) and emotional representations ( $r = -.60$ ,  $p < .001$ ) of illness were inversely related to QOL on the QoLRIQ (Maille et al., 1997).

Similarly, Howard et al. (2009) noted a correlation between panic severity and illness representations of consequences ( $r = .768$ ,  $p = .000$ ) and emotion ( $r = .750$ ,  $p = .000$ ). Individuals with maladaptive (panic) emotional responses had stronger identity beliefs ( $t = 2.734$ ,  $p = .01$ ), longer time-line expectation ( $t = 2.026$ ,  $p < .05$ ), perceived more severe consequences ( $t$

= -2.373,  $p < .05$ , and had greater emotional representation ( $t = -2.093$ ,  $p < .05$ ) than individuals with adaptive (non-panic) emotional responses.

Jessop and Rutter (2003), Horne and Weinman (2002) and Byer and Myers (2000) used CSM informed questionnaires to investigate adherence to asthma medications. Utilizing the Beliefs about Asthma Questionnaire (Jessop & Rutter, 1999) Jessop and Rutter (2003) found that identity ( $t = 2.53$ ,  $p < .05$ ), external cause ( $t = 2.04$ ,  $p < .05$ , and cure-control ( $t = 2.01$ ,  $p < .05$ ) domains of illness representation predicted adherence to asthma medications in multiple regression analysis. Using the IPQ and BMQ, Byers and Myers also found that adherence was significantly correlated with identity ( $r = .40$ ,  $p > .05$ ) in addition to (chronic) timeline ( $r = .30$ ,  $P < .01$ ) domains. Horne & Weinman (2002), also using the IPQ and Brief Medication Questionnaire (BMQ) (Svarstad, Chewning, Sleath & Claesson, 1999), observed a relationship between medication non-adherence and doubts about medication necessity ( $r = .32$ ,  $p < .01$ ).

This review concludes with the cited heart failure studies. Albert and Zeller (2009) examined the relationship between the accuracy of illness beliefs and depression. Using the Survey of Illness beliefs in HF tool to assess illness beliefs, a mean score of 2.99 was obtained, indicating subjects had slightly inaccurate beliefs about HF (mean score  $\geq 3$  indicates accuracy). Accuracy of illness beliefs was related to level of depression ( $r = .224$ ,  $p < .049$ ) due in the most part because of an increased accuracy in beliefs about consequences as depression severity increased. In contrast, Cherrington, Lawson and Clark (2006) reported that knowledge and illness belief in the controllability domain resulted in a positive illness representation, improved compliance and improved outcomes. In a mixed methods study describing why elders delay seeking treatment for acute HF symptoms, Jurgens et al. (2009) employed the IPQ and semi-structured interviews to explore illness perception domains. The most significant contributors to

delay were poor symptom recognition (50%), poor identity (56%), and poor understanding of consequences (56%). The most common coping action was to wait for symptoms to go away. Lack of an emotional response to early symptoms was also surprising, and further compromised early treatment seeking behavior actions. These findings are similar to those of Horowitz, Rein and Leventhal's grounded theory study described above.

In the previous studies, measurement scales informed by the CSM were instrumental in achieving study aims. The specific domains of illness representation were independently measured with these scales and then entered into regression models or correlation matrices with other variables to predict or examine relationships (or mediating factors) between illness cognitions, coping and outcomes.

In summary, the CSM has been useful in describing attribution and treatment delay, explaining coping behaviors and predicting treatment adherence. This framework has great utility for examining factors that influence health behaviors and illness responses. In COPD, patients experience multiple symptoms that fluctuate in severity day-to-day. Internal and external (stress, weather, activity level) factors contribute to this variability. Additionally, their disease course is marked by frequent hospital visits, the use of multiple medications and an undulating emotional state. All of these factors will impact illness representation, coping and appraisal.

Little is known about prodromal (early) symptom awareness and pattern recognition in individuals with COPD who are experiencing a disease exacerbation, despite the frequency of these episodes. Factors that contribute to treatment-seeking delay are also unknown. The CSM offered a framework in which to explore and describe these phenomena. The framework was used to develop interview questions, with attention to targeting each cognitive domain of the



illness representation. The framework also undergirded data analysis, with particular attention to understanding treatment delay.

## **Operational Definitions**

### **Treatment seeking delay (number of days).**

The day from when prodromal or acute exacerbation symptoms were first noticed by the individual, until the time when the individual presented to a health care provider or emergency department for consult.

Prodromal symptoms- The symptoms or group of symptoms that appear before the acute exacerbation onset. Typically include: subtle changes in dyspnea, cold symptoms, sore throat and cough.

### **Prodromal symptom awareness.**

The perceptual awareness of the early onset of prodromal symptoms and/or subtle changes in baseline COPD symptoms indicating a change in health status.

### **Acute exacerbation of COPD.**

An acute, sustained worsening of the patient's condition, from the stable state and beyond normal day-day variations. Includes, but not limited to, the occurrence of increased dyspnea, sputum volume and sputum purulence, increased wheezing, fever, or cold symptoms.

### **Symptom patterns.**

A constellation of symptoms that are unique to the individual and are present with each acute exacerbation experience.

### **Pattern recognition.**

The perceptual awareness of a cluster of symptoms that is consistently present with each acute exacerbation experience.

**Illness representation.** The concrete (symptoms- dyspnea) and abstract (label- COPD) processing of somatic stimuli or functional change that results in the formulation of an illness label (COPD exacerbation) and guides subsequent self-regulating health behaviors. Illness representations contain five cognitive attributes (domains): identity, time-line, cause, consequences and controllability.

**Identity.** The name (label) that is given to symptoms or functional changes based on the individual's ideas about the illness or health threat. In this study the assigned label may be acute exacerbation of COPD, or another labels based their perception of the symptom presentation.

**Time-line.** The perceptions and beliefs about how long the physical, psychological and social impact of an acute exacerbation of COPD will last. Also beliefs about whether their illness is a chronic, acute or cyclic condition.

**Cause.** The external (bacteria, virus, environment conditions), internal (genetics, stress response), and behavioral (smoking) factors believed to precipitate an acute exacerbation of COPD.

**Consequences.** The individual's beliefs about the physical, psychological, social and economic impact of acute exacerbation of COPD.

**Controllability.** The beliefs about whether an acute exacerbation of COPD is amenable to interventions by the individual or health care provider.

## **Chapter 3**

### **Methods**

This chapter outlines the methods used in this qualitative descriptive study that explored patients' prodromal symptom awareness, symptom pattern recognition, and reasons for treatment delay during an acute exacerbation of COPD. Recruitment, data collection, data management and analysis are discussed in addition to strategies used to establish trustworthiness and protection of human subjects.

#### **Design**

Qualitative description was used to describe the acute exacerbation symptom experience and elicit reasons for delay in seeking treatment from the patient's perspective. According to Sandelowski (2000, 2010), qualitative description is the method of choice when trying to uncover the particulars (who, what, where, why) of poorly understood phenomena. The researcher conducting a qualitative descriptive study gathers in-depth, contextual descriptions of a phenomenon of interest, and reciprocally gains insight into complex human experiences (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova & Harper, 2005). Unlike positivist informed quantitative research, which searches for measurable truths, the post-positivist naturalistic underpinnings (epistemology) of qualitative description seeks holistic (ontology) understanding of complex human phenomenon. In this study, the multifaceted experience of COPD exacerbation was illuminated. These findings may assist healthcare professionals to better understand COPD exacerbation from the individual's perspective, and to collaborate with them in improving illness self-management.

## **Setting**

Study participants were recruited from Charlton Memorial Hospital and Tobey Hospital, affiliates of Southcoast Hospital Group located in Bristol and Plymouth Counties, MA. A pulmonologist and a primary care physician, both members of Southcoast Physicians Group, also agreed to participate in study recruitment. However, recruitment from the physician sites was abandoned in February 2012, as recruitment efforts were unsuccessful to that date. The physicians reported that fall and winter 2011-2012 was atypical with few managed in the outpatient setting. Patients in the practices who experienced acute exacerbations presented directly to the emergency room, or were admitted directly from the office. The hospital sites were the recruitment source for patients with moderate to severe acute exacerbation of COPD. The office settings were intended to be the recruitment sites for a sample of participants with mild exacerbation of COPD.

Charlton and Tobey Hospitals are not-for-profit institutions with 362 and 80 beds respectively. Results of a medical record search revealed that between January 1, 2009 and December 31, 2009 there were 1,070 patients admitted with the diagnostic code 491.21, obstructive bronchitis with acute exacerbation, to these facilities. The distribution of admissions month to month totaled between 70 and 103 patients, with the higher rates of admission occurring between January and May. The number of patients treated for acute exacerbation at the physician sites was not available, but was reported to be significant by the participating physicians. Collectively, the inpatient and outpatient recruitment sites were determined to be adequate to provide the necessary number of subjects required by this study.

## Sample

Male and female patients admitted to the local hospitals with acute exacerbation of COPD were recruited. Recruitment was initially aimed at enrolling 50% of subjects from the outpatient setting, and 50% from the inpatient setting to better describe any similarities and difference between groups. However, as previously described, recruitment from the physician sites was subsequently abandoned. Purposive sampling was used to uncover rich, detailed information regarding the acute exacerbation experience and treatment-delay behavior.

Purposive sampling is the purposeful selection of subjects known to have experience, or expertise, with the phenomenon to include in the study (Kemper, Stringfield & Teddlie, 2003). This was guided by the following inclusion and exclusion criteria.

The study inclusion criteria were:

1. Diagnosis of COPD made prior to the current hospitalization or office appointment with the pulmonologist/primary care MD. This was confirmed by pulmonary function test or spirometry results, performed on a date at least one month prior to current health care encounter. When test results are not available, a documented history of COPD in the medical record was used as verification of pre-existing COPD.
2. Recent diagnosis (within 7 days) of acute exacerbation of COPD, defined by hospitalization with an admitting diagnoses of acute exacerbation of chronic bronchitis, acute exacerbation of COPD or pneumonia with acute exacerbation of COPD. Outpatient participants, had recruitment been successful, were to have a diagnosis of acute exacerbation of COPD confirmed by documentation in the patient's office medical record.

3. Ability to read and speak English
4. Age 18 years or older
5. Ability and willingness to provide written consent.
6. Score of 24 or greater on the mini-mental status exam

The study exclusion criteria were:

1. Initial diagnosis of COPD
2. Non-English speaking
3. Co-morbidity of acute heart failure (determined by elevated plasma B-type natriuretic peptide [PBNP] laboratory results) in hospitalized patients.
4. Severe cognitive impairment (MMSE score  $\leq$  23)
5. Unwilling or unable to provide informed consent
6. Hospitalized patients on critical care units
7. Hospitalized patients on mechanical ventilation

The rationale for exclusions was that the researcher is fluent only in English, a co-morbidity of acute heart failure complicates symptom recognition and illness representation, cognitive impairment impairs the informant's ability to meaningfully engage in the research procedures and patients in critical areas and/or mechanical ventilation are assumed to be too ill to participate in research procedures.

A sample size of 14 participants was recruited. Sampling was discontinued when data saturation/redundancy was achieved (Sandelowski, 1995a). Data redundancy was determined to be achieved when well established themes evolved and there was no new information uncovered (Lincoln & Guba, 1985).

## **Recruitment**

The PI met with the hospitals' unit managers and resource nurses as well as office physicians and their office managers to describe the study, explain recruitment procedures and provide contact information. Study flyers, study information sheets, and contact consent forms were provided to the office practice managers at that meeting. A copy of the study proposal and IRB approvals from Southcoast Hospital and UMass Worcester were provided. Additionally, a written script was provided for unit nurses to use when approaching patients to gain permission for the PI to discuss the study with them.

Eligible office patients were to be identified by the office practice managers and informed of the study. Interested individuals were to be given the information sheet that outlined the study title, study purpose, investigator's name and investigator's contact number. Potential study participants would be given the option to either call the PI directly or provide written consent (HIPAA Authorization) to be contacted by the PI by telephone. Once consent was confirmed, the PI would contact potential participants by phone to arrange a time to meet in their home. As no participant's were recruited from the office settings, these procedures were never initiated.

In the hospital setting, potential study participants were identified by the unit resource nurse. Permission for the PI to visit with each potential participant was obtained either by the resource nurse or primary care nurse using the standard written script provided by the PI. Before making contact with any potential participant, eligibility based on diagnosis and ability to speak English was confirmed with the RN.

During the initial face-to-face contact with potential participants, the PI explained the purpose of the research study, provided an opportunity for questions to be answered, and

obtained written consent. HIPAA authorization was also obtained as part of the consent process to access the participant's health record for the purpose of documenting COPD severity and/or confirming the absence of an acute heart failure diagnosis. The informed consent document also included permission for the PI to re-contact the participant for the purpose of clarifying or verifying data at a later date as needed. Participants were informed that they could withdraw from the study at any time. All participants were given a copy of the consent, with the original copy retained by the researcher and secured in a locked file. A numeric code was assigned to each participant, and recorded in a recruitment log that was also be maintained in a locked drawer separate from other study documents. A \$25.00 American Express gift card was given to all participants who participated in the study.

### **Procedures**

After ensuring patient comfort, safety and privacy the study measures and interviews were conducted (Figure 2). Participants were interviewed in their hospital room or a private conference room on the unit.



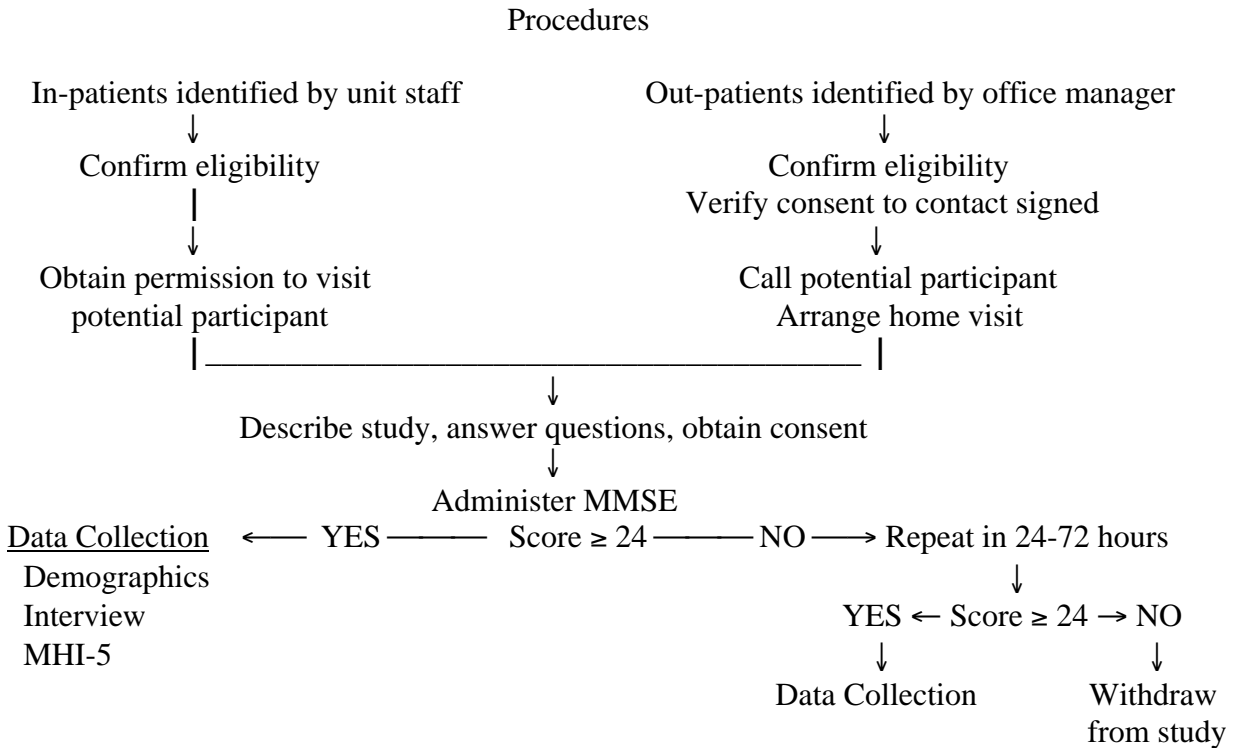


Figure 2. Data collection procedures

The Mini Mental State Exam (MMSE) (Folstein, Folstein & McHugh, 1975) was administered to assess mental status. This was important as disease related factors such as hypoxemia, hypercarbia and steroid use can alter cognition and impair recall and decision making (Meek et al., 2001). The MMSE is a valid and reliable instrument (test-retest  $r = .89$ , interrater reliability  $r = .82$ ) that has been used extensively in clinical practice and research since 1979. It is an 11-item measure that tests five areas of cognitive function: memory, attention, recall, orientation and calculation ability. A score of 23 or lower (maximum 30) is indicative of cognitive impairment. Administration time was 5-10 minutes, as estimated by Folstein et al. (1975). If a participant had failed to obtain a score of 24 or greater on the initial assessment, no further procedures were to be administered, and the participant was to be reassessed within 1-3 days. If a participant failed the MMSE on the second assessment, then he/she would be

withdrawn from the study and no additional study procedures to be conducted. No participants attained a score less than 24 in this study.

Demographic and clinical data were collected from the participant and/or patient health record and recorded on the data extraction sheet (Appendix A) for the purpose of describing the sample. Data collected included age, gender, ethnicity, education, marital status, smoking history, exposure to second hand smoke in the home, years with COPD diagnosis, number of prior hospitalizations with COPD exacerbation, date of last exacerbation (approximate) and COPD medication use. Pulmonary function tests were also obtained from the medical record for the purpose of assigning a COPD stage according to GOLD criteria.

The qualitative interview followed. They were semi-structured, following an interview guide (Appendix B) informed by dimensions of Leventhal's 'common-sense' model (Leventhal, Meyer & Nerenz, 1980). Face-to-face interviews were conducted by the PI with the aim of deriving rich descriptions of prodromal symptom awareness and pattern recognition associated with participants' current exacerbation experience. Contextual factors that impacted treatment-seeking behaviors, in particular treatment delay were also elicited. A calendar was utilized to provide a visual, contextual cue that may assist participants in more accurately determining when their symptom(s) occurred. After administering to the first participant, data collection procedures were assessed by the PI and dissertation advisor to determine effectiveness of procedures, calculate time required for procedures and evaluate patient comfort. Interviews were audio recorded using one pretested digital recording device and a traditional tape recorder. Field notes were maintained to record non-verbal observations and personal reflections that enriched and augmented the audio transcription (Creswell, 2003). Data collection continued until data saturation occurred (Sandelowski, 1995a).

The five-item Mental Health Inventory (MHI-5) subscale of the SF-36 (Ware & Sherbourne, 1992) was administered at the conclusion of the interview. This brief scale measures anxiety, depression, loss of control and psychological well-being of individuals (Berwick et al, 1991). Internal consistency of the MHI-5 was demonstrated with a Cronbach alpha of 0.74. The MHI-5 performs best in screening for mood disorders (AUC: sensitivity 0.83; specificity 0.78) and anxiety disorders (AUC: sensitivity 0.73; specificity 0.60) (Rumpf, Meyer, Hapke & John, 2001). For the assessment of depression, a calculated score  $\geq 52$  on the MHI-5 indicates absence of symptoms and a score  $< 52$  indicates presence of symptoms (Arroyo et al., 2004). This data was important for describing the study sample.

### **Data Management**

All forms, measurement tools and audio files for each participant were de-identified and assigned a code number. They were maintained in individual folders labeled with the assigned participant code. Folders were stored in a locked file cabinet within the PI's private locked office. A record of each participant and their unique code was maintained in a recruitment log that was secured separately in a locked draw within the same office. The researcher's reflective journal, field notes, audit trail and data analysis coding sheet were also secured in the same locked file cabinet.

After each participant session, the digitally recorded interview was forwarded to a professional transcriptionist and transcribed verbatim into a word-processed document. Transcripts were forwarded and returned electronically through Files Direct, a secure password protected, HIPPA approved service. Upon electronic return of each transcript, the PI proofed it against the audiotape for any inaccuracies. Field notes collected during the interview were transferred onto the transcript. These provided background and insight into verbal and non-

verbal communication that occurred during the interview. Electronic copies of the transcript were stored in a file on the PI's password protected computer and backed up in the PI's file on the UMass Dartmouth server. A hard copy of the transcript and corresponding back up audio taped recording was placed in each participant's study folder.

All electronic files were backed up on the server at the University of Massachusetts Dartmouth, where the PI maintains her office. Only the researcher had access to the computer on which data was stored, and to the locked data.

### **Data Analysis**

Consistent with the tenets of qualitative description, data collection and data analysis occurred simultaneously, and subsequent sampling and interview probes modified accordingly to achieve maximum exploration of themes to the point of redundancy. In the following paragraphs the data analysis procedures used to address each specific aim are described, followed by a description of the content analysis process.

#### **Aim 1: Explore awareness of prodromal symptoms in the days preceding an acute exacerbation of COPD.**

To address this aim, interview transcripts were analyzed for prodromal symptoms reported in response to guided interview probes. These symptoms were entered on the symptom data collection sheet. The number of subjects who report awareness of prodromal symptoms were calculated. Additionally, the frequency of individual prodromal symptom experienced across all subjects, were calculated.

#### **Aim 2: Describe symptom patterns associated with acute exacerbations.**

Interview transcripts were examined for the presence of a unique acute exacerbation symptom pattern, evidenced by participant description of a prior presentation of the same cluster

of symptoms on at least one occasion. This data was transferred to the symptom data collection sheet. The incidence of each cluster of symptoms was calculated and classified by the Anthonisen typology of acute exacerbation.

**Aim 3: Identify dimensions of illness representation (identity, time-line, cause, consequence, controllability) in individual descriptions of treatment-seeking delay during exacerbation of COPD.**

The median time of treatment delay was calculated. Delay time was calculated from the day the patient reported exhibiting a symptom change, determined using modified Anthonisen Criteria, and the day on which the health care encounter occurred. Variables (age, gender, ethnicity, marital status, education level, disease severity, disease length, smoking status, and insurance status) and treatment delay were also examined to identify any trends. Non-parametric statistical measurements were used to detect associations and differences between variable, however the small sample size render the results statistically non-significant.

#### Qualitative content analysis.

Data was analyzed using qualitative content analysis. Content analysis institutes a systematic method for developing codes, and themes from transcribed interview data. Pertinent data chunks from each transcript were pulled out of the text, coded and categorized, then reorganizing into focused descriptive themes that explained the phenomenon of interest (Hsieh & Shannon, 2002; Knafl & Webster, 1988; Miles & Huberman, 1994; Sandelowski, 1994). Coded data was compared and contrasted within and across subjects (Knafl & Webster, 1988) as well as compared to the dimensions of the guiding framework (Sandelowski, 1995). Content analysis proceeded as follows:

1. The PI read transcript in entirety several times to appreciate the overall gestalt and to develop initial insights.
2. A preliminary summary reflecting first impressions and general analysis of each transcript was word-processed.
3. Transcribed interviews were reviewed against audio-recording and each line of the transcript individually numbered. Key passages were highlighted and notated. Associated field notes were transcribed into each document.
4. Transcripts were deconstructed and key segments sorted and coded in chunks that represented the key concepts specified in research aims. These were cut and pasted into individual word document files.
5. A codebook was maintained clearly defining each code and category, and explicating the category inclusion criteria for consistency within and across transcripts. As new codes and/or categories emerge from the data, the definitions and categories were modified as needed.
6. Once the general categories were established from all the data, they were analyzed and collapsed into more abstract themes.
7. Using constant comparison techniques, patterns of similarities and differences in categories and themes within and across participants were examined. Interview probes were modified to facilitate this exploration.
8. Themes were compared and contrasted in relationship to the framework.

### **Trustworthiness**

The analysis and findings of qualitative research findings must be shown to be “systematic, objective and worthy” (Wolf, 2003, p. 175). Lincoln and Guba (1985) refer to this

illumination of rigor in research procedures as trustworthiness. Trustworthiness in the naturalistic paradigm parallels the positivist concepts of reliability and validity. The components of trustworthiness include transferability, dependability, confirmability and credibility (Lincoln & Guba, 1985)

Transferability is loosely comparable to the concept of internal validity (generalizability) in quantitative research. It refers to the extent in which findings can be applied to other contexts or populations. In qualitative methods this is accomplished through the use of appropriate sampling techniques and by obtaining thick, rich descriptions of the phenomenon under investigation. In this study, the PI used purposive sampling to obtain rich descriptions of the acute exacerbation experience (Lincoln & Guba, 1985). Vivid descriptions of participants experiences, supported by quotes, and a clear representation of established themes was included in the report of findings to support transferability.

Dependability mirrors the quantitative concept of reliability and confirmability the concept to objectivity. Evidence of rigor in these components is demonstrated through maintenance of an audit trail, or documentation of the research process (Lincoln & Guba, 1985). An audit trail is written documentation of data analysis decisions and inferences that start with the transformation of raw data into codes and themes, and culminates in the report of study findings. An audit trail file was maintained by the PI and contains personal reflections, bracketed biases and preconceptions and methodological decisions. Decisions and rationales made regarding sampling, changes in interview questions or probes, coding decisions, category and theme development and data analysis were documented.

Credibility is compared to internal validity in quantitative methods. In qualitative methods it represents confidence in the interpretation of data (Lincoln & Guba, 1985).

Credibility infers that the findings are authentic and represents the emic perspective of participants (Sandelowski, 1994; Whitemore, Chase, Mandle, 2001). Credibility was established in this study by prolonged engagement with subjects and data. This was accomplished by providing adequate time for patient interviews, avoiding premature closure of data collection, and collecting data until saturation was accomplished. Participating in peer debriefings with the dissertation advisor via email and phone conferences meetings to review procedures, coding decisions and analysis also strengthened credibility of findings. An audit trail folder containing documentation of the PIs reflections, and process decisions was maintained. Lastly, as recommended by Lincoln and Guba (1985) member checks were conducted with participants to verify themes, and the author's interpretation of the data.

### **Member Checks**

After the main theme and subthemes were delineated, three participants were contacted by phone for the purpose of verifying that the themes accurately described the acute exacerbation experience. After defining and providing content exemplars of the main theme and subthemes, participants agreed that the themes semantically and descriptively represented their experiences. One participant vehemently acknowledged the analysis stating, "That's exactly how it goes." Another stated, "That's a good description of the process I go through." The three member check participants reiterated their experiences as discussed during the interviews and one participant elaborated on her feelings of being stigmatized by healthcare workers.

### **Reflexivity**

In qualitative studies using a naturalist paradigm, the researcher serves as the instrument, remaining very close to the data during collection and analysis phases (Lincoln & Guba, 1985). Additionally, the relationship between the researcher and the participant is an important tool in



extracting rich, detailed data (Milne & Oberle, 2005). The intimacy of this relationship requires that the researcher remain cognizant of any personal or professional biases and preconceptions that may be inadvertently imbued during data collection or analysis (Lincoln & Guba, 1985; Malterud, 2001). Reflexivity, or purposeful analysis of any researcher influence on the research process, is a necessary component of qualitative research because of this relationship (Koch & Harrington, 1998). Koch and Harrington (1998) recommend the use of a journal to bracket biases and demonstrate reflexivity. Documentation of the researcher's self-reflection on the challenges inherent in separating their nurse role and experiences from their researcher role also enhances credibility of research findings (Dowling, 2006).

The PI has 30 years experience in acute and critical care nursing, working closely with individuals who have experienced exacerbation of COPD. This experience was beneficial in developing rapport with subjects and inserting appropriate probes into the interview, however the researcher needed to consciously refrain from leading the respondents and making assumptions about the meaning of vague responses during the data collection and data analysis processes (Milne & Oberle, 2005). Preconceptions formulated from prior professional experiences were acknowledged and recorded in a journal to ensure that individual experiences were interpreted without bias.

### **Ethical considerations**

The health and well being of each participant remained the utmost concern. When a participant exhibited dyspnea ( $n=1$ ) and emotional distress ( $n=1$ ) during the procedure, data collection was halted until the participant recovered physically and emotionally. Interviews continued when the participant verbalized willingness and readiness to continue. As an experienced clinician with over 25 years of experience with individuals with COPD, the researcher was competent to recognize the signs and symptoms of distress in this population.

Health care consult was not required, however, the patient's primary care nurse would have been summoned if necessary. In the interest of patient safety, one participant's self-report of suicidal ideation was reported to the resource nurse and subsequently her primary care physician.

### **Human Subjects Consideration**

Approval was obtained from the Internal Review Board of Southcoast Hospital Group, which oversees research conducted at Charlton Memorial Hospital and Tobey Hospital, the inpatient sites from which patients were recruited. Approval was also obtained from the IRB at the University of Massachusetts Medical School, Worcester, MA where the researcher is enrolled in doctoral studies.

Written informed consent was obtained from participants at the initial researcher-participant encounter. Subjects were informed that participation was voluntary, that care would not be influenced by a decision not to participate, and that they had the right to withdraw from the study at any time. Individuals were informed that their participation in the study was confidential, and that study data was not part of their medical record. Methods for ensuring safety of data and how information would be used were detailed. The consent included access to medical records, permission to notify health care provider if participant experienced physical or emotional distress, and for phone follow-up if necessary. Risk-benefits were discussed, and patients were given ample opportunity to ask questions. Two copies of the informed consent were obtained. Each participant received one copy, and the researcher retained one copy.

### **Risks-Benefits**

There were no direct benefits to individual study participants. However, the knowledge gained from this study may help COPD patients in the future by increasing knowledge and

understanding of symptom recognition during acute exacerbation of COPD, and the reasons patients delay seeking treatment. This information may guide future intervention development, such as action plans, and patient education.

Potential risks to the patient-participant included emotional discomfort in reviewing the symptoms and decision-making they enacted during their acute exacerbation. Physical discomfort during the interview, related to the additional physiologic demand conversation places on the respiratory system was also a potential risk. Had significant emotional or physical discomfort occurred during the interview, the interview would have been discontinued and appropriate assessment and interventions delivered by the appropriate medical staff member.

### **Summary**

This study, employing a qualitative descriptive design, describes the little-known phenomena of prodromal symptom awareness, pattern recognition and the reasons individuals delay seeking treatment during acute exacerbation of COPD. Leventhal's "common-sense" Model (Leventhal, Meyer & Nerenz, 1980) guided the development of the interview guide, data analysis and discussion of findings. The goal of this study was to obtain knowledge and understanding that can guide the development of patient interventions so that acute exacerbations of COPD will be identified and treated earlier. Early treatment reduces the negative consequences of exacerbation and improves health outcomes for patients with COPD.

## Chapter IV

### Results

#### Introduction

Qualitative description was used to explore the acute COPD exacerbation experience. The primary focus of this study was to explore participant awareness of prodromal symptoms and exacerbation symptom patterns as well as factors that delay treatment-seeking during an acute exacerbation. Face to face semi-structured interviews were conducted with fourteen individuals during their hospitalizations for acute exacerbation of COPD. Qualitative analysis revealed a main theme of *Recognizing, Responding and Reacting to Change*. This theme represents participant recognition of impending acute exacerbation, and subsequent illness management responses and emotional reactions. Six subthemes were linked to the main theme: *something's coming, here we go again, seeking urgent treatment, riding it out, not in charge anymore and my last day*. The subtheme *something's coming* reflects the participant's awareness of symptoms that are a change from their typical day-to-day COPD symptom variation. *Here we go again* represents the participant's recognition of their acute exacerbation symptom pattern and what is to follow. Participants reacted to their baseline symptom change by *seeking urgent treatment* or by *riding it out* and engaging in self-management behaviors in the hope that symptoms would resolve spontaneously. As a result of their exacerbation event and its impact, participants described feeling as if they are *not in charge anymore* of their life and many felt as if it were their *last day* when their symptoms reached peak acuity.

#### Participants

Twenty-one individuals hospitalized in two community hospitals in Southeastern Massachusetts were identified as potential study participants by the unit resource nurses, and agreed to discuss

the study with the Principal Investigator (PI). After discussing the study requirements one individual declined to participation due to fatigue, another declined due to feeling "short of breath and panicky" and a third individual stated that he was not appropriate because he had "lung cancer not COPD. "Four additional individuals who consented to participate had to be excluded upon chart review because their laboratory results (pBNP) indicated the presence of concomitant heart failure (exclusion criteria). The remaining fourteen individuals met inclusion criteria and were enrolled. Data collection took place between October 2011 and February 2012.

The sample included five male and nine female participants with a mean age of 66.21 years (median 65, range 49-87). All participants had medical insurance. The ethnic distribution of participants included 11 non-Hispanic whites, one Cape Verdean, one West Indian and one individual of Portuguese decent. Six participants were married, four were divorced, three were widowed and one was single. The majority of participants were high school educated, with 50% ( $n = 7$ ) of the sample having post-secondary education. Participants had moderate ( $n = 6$ ) to severe ( $n = 8$ ) COPD based on GOLD classification (see Table 1). The mean number of years since diagnosis of COPD was 7.75 (SD = 5.0) during which time participants experienced an average of 3.29 (SD = 3.75) exacerbations a year, resulting in an average of 4.14 (SD 4.04, range 1-17) hospitalizations yearly. All of the participants had a history of cigarette smoking and 28.6% ( $n = 4$ ) were current smokers. A summary of this data is included in Tables 8 and 9.

Table 8

*Sample characteristics for categorical variables*

Variable	n	%
Gender		
Male	5	35.7
Female	9	64.3
Marital status		
Single	1	7.1
Married	6	42.8
Widowed	3	21.5
Divorced	4	28.6
Education		
Some HS	2	14.3
HS Degree	5	35.8
Some College	1	7.1
AD	3	21.4
BS	1	7.1
MS	2	14.3
Ethnicity		
White	11	78.6
Portuguese	1	7.1
Cape Verdean	1	7.1
West Indies	1	7.1
Smoking status		
Current Smoker	4	28.6
Previous Smoker	10	71.4
COPD severity (GOLD staging)		
Stage I Mild	0	
Stage II Moderate	6	42.8
Stage III Severe	8	57.2
Stage IV Very Severe	0	
Insurance		
Medicare	8	57.1
Mass Health	2	14.3
Private	4	28.6

Table 9

**Sample characteristics for continuous variables**

Variable	N=14	
Age	Mean	66.21
	Median	65
	SD	(12.09)
	Range	49-87
Years since COPD diagnosis	Mean	7.75
	Median	5.0
	SD	(9.93)
	Range	1-40
Exacerbation rate (# per year)	Mean	3.29
	Median	2.0
	SD	(3.75)
	Range	1-15
Hospitalizations per year	Mean	4.14
	Median	3.0
	SD	(4.04)
	Range	1-17
Years smoked	Mean	34.21
	Median	34
	SD	(18.27)
	Range	5-60
Calculated pack years	Mean	42.71
	Median	30
	SD	(32.19)
	Range	5-100
Treatment delay (# days)	Mean	7
	Median	7
	SD	(4.96)
	Range	0-14
MHI-5 (N=11) Score range 0-100 < 52 = depression symptoms	Mean	67.27
	SD	(23.9)
	Range	32-100
	Alpha	.913
MMSE Scores Possible range 0-30 ≤ 23 = cognitive impairment	Mean	27.71
	Median	28
	SD	(2.05)
	Range	25-33

**Gender differences**

Of the five male and nine female participants in this sample, more male participants were married (60%) and had Stage III COPD (80%). Participants in this study did report being encouraged by their spouses to seek treatment, although there was no significant difference

in treatment delay between married and unmarried participants, or between male and female participants (6.8 vs. 7.0 days) in this study.

### **Smokers vs. nonsmokers**

Two of the four current smokers continued to smoke despite directly associating their current, and prior, acute COPD exacerbations to smoking. One participant stated that after 53 years she had reduced the amount she smoked, however “just can’t seem to quit completely.” The other participant described full awareness of the impact of smoking on her exacerbation rate, disease progression and mortality, resolving to finally quit. She stated, "This is a last chance for me."

The remaining two participants who smoked linked their COPD to smoking, but did not identify smoking as a cause of their exacerbations (or current exacerbation). One participant who smoked 2 packs of cigarettes per a day for over 40 years reported quitting on a prior occasion “until he snapped.” After a “bad day” he resumed smoking despite understanding the health consequences. On the day of the interview the patient stated he had decided to quit smoking. “I have a choice to smoke or breathe and if I keep [smoking] I won’t be doing either one for long.” The fourth participant, who had recently been diagnosed with COPD, was gradually reducing her cigarette consumption at the time of her exacerbation. She does not intend to resume smoking upon discharge.

All four participants were counseled regarding the importance of smoking abstinence by their healthcare providers. Southcoast Hospitals offered participation in the Quit Works smoking cessation program to each participant who currently smoked.

### **Depression**

Three female participants scored less than 52 on the MHI-5, indicating the presence of



depressive symptoms. At the conclusion of participant interviews, this subscale was administered to individuals who were not too fatigued ( $n = 11$ ) to complete an additional measure. The scale was administered for the purpose of describing the sample. Other than gender (female) and ethnicity (Caucasian) there were no commonalities in the characteristics of individuals with depressive symptoms.

Although two participants were among the younger (49, 52) aged participants, two other participants in the same age group were not noted to have depressive symptoms on the MHI-5. Of the participants ( $n = 11$ ) who completed the MHI-5, the individual with the greatest number of years since COPD diagnosis (12) did score in the depressive symptom range. However, the remaining two participants were more recently (1, 4.5) diagnosed with COPD. In contrast, the participant with the greatest number of yearly acute COPD exacerbations (15) and hospitalizations (17) was not found to have depressive symptoms on the MHI-5. Participants who had a score indicating the presence of depressive symptoms ( $n = 3$ ) experienced between one and three COPD exacerbations and hospitalizations yearly, as did participants ( $n = 7$ ) who were not found to have depressive symptoms on the MHI-5.

During the interview, one participant (MHI-5 =40) described being very depressed when she could not breathe during this exacerbation episode. “I even had thoughts of that really bad ‘S’ (suicide) word.” A second participant (MHI-5 =36) did not specifically describe being depressed, but did discuss being frightened by the severity of her dyspnea on the day of her hospital admission. Interestingly, she had resisted recommendation by friends to seek healthcare sooner. Both of these individuals delayed seeking treatment for 14 days. The third participant with an MHI-5 score indicative of depressive symptoms (MHI-5 =32) also did not directly address feeling depressed, nevertheless she did discuss her disappointment in not being eligible

for lung transplant. Furthermore, she discussed preparing a “bucket list” and other end-of-life activities. Each of the participants who scored < 52 on the MHI-5 were currently being treated by their primary care physician for depression.

### **Treatment delay**

The variable of treatment delay was also analyzed for commonalities among participants who delayed seeking treatment for seven days or more, as well as differences between those who delayed more than seven days and those who sought treatment sooner. One finding of note was that two of three participants who delayed seeking treatment the longest (14 days) had depressive symptoms according to the MHI-5. Their treatment seeking behavior is discussed above. An additional finding was that the participants ( $n = 2$ ) with the highest yearly frequency of acute COPD (7, 14) exacerbations only delayed treatment seeking for two days. These individuals reported recognizing the signs of their exacerbation and its consequences. No other commonalities or differences were noted across characteristics within the treatment delay group or between treatment delay and non-treatment delay groups. No relationship between any variable and treatment delay was found.

### **Themes and Subthemes**

The main theme and six subthemes represent the physical, cognitive, and emotional experiences of individuals hospitalized for acute exacerbation of COPD. A rich description of the themes and subthemes, supported by participant quotes, follows.

#### **Recognizing, responding and reacting to change**

The main theme of recognizing, responding and reacting to change is threaded throughout all participant descriptions of their acute exacerbation of COPD experience. This theme represents the participant’s recognition of a change in their baseline COPD status, their

response to change in the form of self-care or treatment seeking, and their emotional reaction to the exacerbation event.

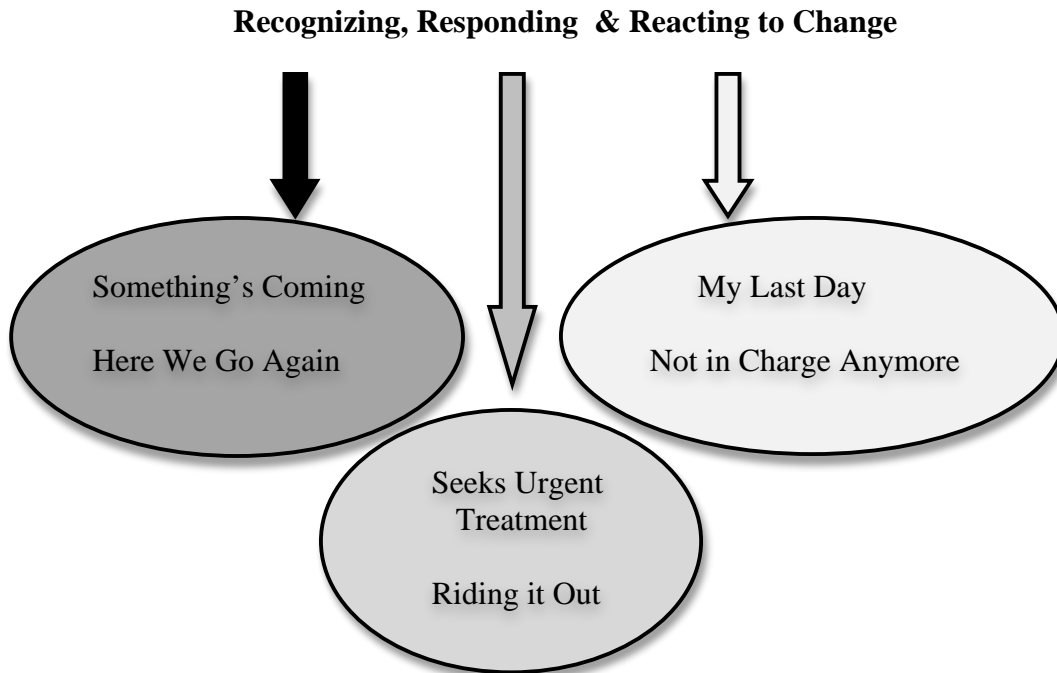
COPD exacerbations can present insidiously over days, or abruptly over minutes. A pre-exacerbation prodrome of vague symptoms such as headache, fatigue, and upper respiratory symptoms preceded exacerbation onset by one to four days in individuals who had a crescendo-type exacerbation onset. However, the majority of these participants did not understand these vague symptoms to be a precursor of exacerbation. Prodromal symptoms are typically different than exacerbation symptoms, but serve as a warning sign and trigger for exacerbation. Of the individuals who experienced an abrupt exacerbation onset, most were unaware of having any prodromal symptoms in the preceding days.

In the course of the interviews, participants came to recognize that they had a recurring pattern of exacerbation symptoms that was a qualitative or quantitative change in their typical daily symptoms such as worsening dyspnea, change in sputum character or quantity, or the development of wheezing. In most individuals, this pattern was the same with each exacerbation but the patterns varied across individuals, based on the underlying component of their COPD (emphysema vs. bronchitis) and the etiology of their exacerbation (infectious vs. environmental). Most participants intuitively recognized their symptom worsening as a “flare-up” of their COPD, or acute exacerbation, based on a prior experience with a similar pattern of symptoms occurring with a prior diagnosed exacerbation(s). However participants only became consciously aware of their repeating symptom pattern during the study interview discussion.

The participants responses to exacerbation onset was most influenced by the abruptness and severity of exacerbation symptom presentation. Participants who experienced a precipitous onset of symptoms presented to the emergency room immediately for treatment because of the

life-threatening severity of their dyspnea. Participants who experienced an insidious onset more often delayed seeking treatment until it became evident that their self-management behaviors of activity reduction, medication adjustments and breathing techniques were unsuccessful or they became incapacitated by their symptoms. At this point participants either contacted their health care provider or presented to the emergency room. Participants who had their exacerbation successfully managed on an outpatient basis by their pulmonologist or primary care physician in the past were more likely to initially contact their physician for treatment. Participants who had little success with prior outpatient management, or who have been directed by office staff to the emergency room on prior occasions, more often chose the emergency room as their initial healthcare contact for exacerbation management.

Emotional reactions to the exacerbation experience were as divergent as the individual symptom presentation themselves. Participants described feelings ranging from simple frustration over being ill again to an overwhelming fear of impending death due to the severity of their breathlessness. Furthermore, psychosocial factors played a role in treatment seeking delay. Participants reported financial concerns, social obligations, attempting to maintain control over life and illness, avoiding healthcare interactions and stubbornness as reasons that contributed to delayed treatment seeking. Six subthemes (Figure 3) were linked to the main theme of *recognizing, responding and reacting to change* and more fully describe each of the main theme's components. These subthemes are further described with exemplars below.



*Figure 3: Themes and subthemes*

### **Something's Coming**

Something's coming, a subtheme of *recognizing, responding and reacting to change*, refers to the initial recognition of a health status change. All participants ( $N = 14$ ) described an awareness of a change in their baseline COPD symptom status that occurred from a few hours to two weeks prior to seeking healthcare. Participants compared their new or worsening symptoms to the way they usually felt as the primary way of sensing a significant change in their baseline disease status. They also compared their current activity tolerance for typical activities to their usual tolerance as a gauge for assessing changes. For example, "I noticed that my activities have dropped, you know to eat, prepare a meal took a great deal out of me "and" the stairs were a little heavier...for me to climb, harder." Although all participants recognized the onset of new symptoms or a change in symptoms or functional status, not all of them evaluated these changes as a prodrome to impending acute COPD exacerbation. They sometimes believed they were "just tired" from doing too much or simply coming down with a simple cold. The vagueness in

the statement "I knew *something* was coming" by two participants illustrates the ambiguity participants were confronted with when trying to differentiate their symptoms. They knew they were "coming down with something" but were not certain if it was COPD related. Two participants did admit to having difficulty distinguishing between "a bad day" on their dyspnea symptom continuum from a severity point that could signal impending exacerbation. The participant who experienced sputum changes with his exacerbation onset found it much easier to discern between baseline and exacerbation state, as there was a marked qualitative and quantitative change in usual sputum production. The sputum character change also marked the crossover point from illness prodrome to exacerbation for this individual.

In total, eleven participants described an illness prodrome that preceded the onset of their acute exacerbation of COPD. The symptoms experienced during this time period were not "classic" exacerbation symptoms, differed from the individual's day-to-day symptom variance and made them aware that "something was coming on." The prodromal symptoms reported by study participants included: palpitations ( $n = 1$ ), sinusitis ( $n = 2$ ), headache ( $n = 2$ ), fatigue ( $n = 8$ ) and cold symptoms ( $n = 8$ ). Although more than 50% of individuals ( $n = 8$ ) experienced a variety of cold symptoms, fatigue seemed to be the most bothersome symptom. Participants gave detailed descriptions of how fatigue impacted their daily functioning. One participant stated "[I was] tired all the time...I'd sleep, wake up in an hour, sleep again." Other participants describe fatigue and decreased functional ability, explaining "I felt more tired; I couldn't do as much walking as I usually could" and "I had absolutely no energy. I was so worn out I didn't want to go out, visit with friends or even eat my meals."

Although eleven participants were aware of the presence of prodromal symptoms retrospectively, only four participants specifically identified their symptoms as being a prodrome

of their COPD exacerbation. This is exemplified in the participant comment "[I thought] the same thing is happening", which was echoed by two additional participant statements of "I knew what was happening because I've been down that road so many times." and "I just knew it was coming on[again]." The fourth participant, who has frequent exacerbations, recognized his signs of impending exacerbation and self-initiated his physician prescribed action plan. Another participant discussed never knowing that cold symptoms can present as a prodrome to an acute exacerbation episode and shared having a newly learned understanding of this relationship after researching symptoms on the internet during this current exacerbation episode. As she reported,

I came down with a cold, a head cold, and I didn't [know] that chronic bronchitis can... start with a cold and a headache...and I googled it and it said a COPD exacerbation starts [as a] cold and then it goes to your lungs.

Three participants denied having a prodromal illness period, reporting instead sudden onset of severe (or worsening) dyspnea, without any precipitating or accompanying symptoms. These individuals immediately sensed something was wrong associated with COPD, and knew they needed prompt medical attention. One participant reported awaking in the early morning hours and "not being able to breathe" further stating that "it felt like somebody just shut my lungs down." In retrospect, he admitted that he had felt a little more tired than usual on the prior day and maybe a little short of breath during the evening. Upon reflection, the remaining two participants also admitted to being a little more fatigued in the days prior to hospital admission. However, these individuals experienced fatigue simultaneously with an increase in perceived dyspnea, so it is not clear if the fatigue was a prodromal symptom or a consequence of the individual's dyspnea and subsequent increased work of breathing. Nevertheless, fatigue was

described by all three participants as being a significant indicator of a change in their COPD baseline status just prior to exacerbation onset.

### **Here We Go Again**

Here we go again is the second subtheme related to the recognizing change component of the overarching main theme. It relates to the transition from prodromal symptom awareness to exacerbation symptom recognition. Although not all participants experienced, or were aware of experiencing prodromal symptoms, exacerbation symptom patterns were more readily described during the interviews. Through questions and probes, a pattern of exacerbation symptoms that recurred with more than one exacerbation event was illuminated. The presence of a recurring pattern of exacerbation symptoms was confirmed by 13 of 14 participants in the study. This was the first COPD exacerbation for the remaining participant; therefore she had no prior experience upon which to draw on for pattern recognition. Four study participants were cognizant of their own specific exacerbation pattern without needing to be guided to this realization. This was evident in statements such as “that’s how it always is...it’s the same pattern it doesn’t change” and “it’s the same symptoms that I’ve been getting for the last five to six years, every three to four months” and “here we go again.” Another participant not only recognized her personal symptom pattern, but a recurring hospitalization pattern when stating, “it’s the same each time, it builds then I have to go [to the hospital]”. Although the individual symptom that comprised the pattern for each individual differed amongst individuals, the pattern remained consistent across exacerbations within each individual.

The remaining participants came to recognize they had a consistent exacerbation symptom pattern during the course of the interviews. As a result of directed probes, an epiphanal moment of recognition occurred. This is evident in one participant’s response: “Could be, could



be coming one [a pattern].” Data analysis revealed that the majority of participants in this study ( $n = 8$ ) experienced Anthonisen Type 3 (Table 6) exacerbations. Table 10 describes the symptom patterns of participants in this study.

Table 10

*Exacerbation Symptoms with Anthonisen Typology Classification*

Symptoms	<i>n</i>	Anthonisen Classification
Increased dyspnea, sputum amount and purulence	1	Type 1
Dyspnea, sputum	1	Type 2
Increased dyspnea, cough, sputum amount	4	Type 2
Dyspnea, wheezing, anxiety, sleeplessness	1	Type 3
Sudden onset SOB	4	Type 3
Dyspnea, wheeze	1	Type 3
Dyspnea, cough	1	Type 3
Dyspnea, cough, wheeze	1	Type 3

### Seeking Urgent Treatment

Responding to change, the second component of the main theme, is represented by two subthemes. The first subtheme, *seeking urgent treatment*, represents the immediate recognition of a life-threatening change in health by participants, and subsequent seeking of treatment early in the course of their event. Three participants in this study experienced a sudden onset of severe dyspnea, and responded by seeking urgent treatment within 2 to 48 hours of symptom onset. This early treatment seeking was influenced by the severity of their dyspnea during the event, as well as having a prior similar exacerbation experience. The rapid onset and acuity of their symptoms caused them to be frightened, leading to a greater sense of urgency in seeking care. One participant stated:

I woke up twice during the night a little [short of breath], I sat up, calmed myself down, took a couple deep breaths, [used] my inhaler, went back to sleep. I woke up again being unable to breathe. I took my inhaler, I said its 3AM I might as well get up and get ready for work anyway and take a shower. I went in, got in the shower. I was in the shower long enough to get wet and soapy and that was it, it felt like somebody shut my lungs down, it felt like I couldn't expel any air. I banged on the door for [my wife] to call 911. I don't think I finished rinsing the soap off. I put my jeans on...and went out on the porch to get some cold air in me. I almost went to the floor twice. I was real lightheaded, like I was going to pass out. Being a guy, we don't like to do that; we're supposed to be tough. I was out [on the porch] for a few minutes and then I came in and sat in the chair. I was going to wait out front for the ambulance and she [wife] talked me into sitting down in the dining room and wait[ing] for them (911) to come. When the ambulance got there they put the mask on me. I kept fighting the mask. But it was real, real panic.

This participant reported that a similar episode had occurred one year prior, and he remembered from that experience that time was of the essence. Another participant who presented early for treatment shared a similar experience:

I know [when] I'm in full exacerbation...everything shuts down. I know I'm in trouble when none of my rescue inhalers or nebulizers work. Nothing (air) was getting in. [My husband] thought I was on my way out.

This participant contacted her healthcare provider and was directed to present to the emergency room promptly. This patient also had prior experience with a significant exacerbation, and understood the consequences associated with treatment delay. The third participant who sought

treatment within 48 hours of dyspnea onset also had prior severe exacerbation experience, and was able to get an appointment with her pulmonologist within hours of calling for an appointment. She was seen and immediately referred to the emergency room. In all these examples a combination of symptom severity, prior exacerbation experience, early recognition and/or healthcare provider advice contributed to early presentation for treatment.

### **Riding it out**

The second subtheme related to responding to change is riding it out. Riding it out refers to a wait and see approach to illness management. This decision making process contributed to treatment delay (time from exacerbation symptom onset to engaging healthcare) that ranged from two days to two weeks. The decision to ride it out was described as being influenced by many factors including personality traits such as stubbornness ( $n = 2$ ) and psychosocial factors such as prioritizing social commitments over health concerns ( $n = 3$ ), stigmatization ( $n = 2$ ) and avoiding hospitalization ( $n = 6$ ). Many participants used this approach despite assessing their illness as an exacerbation ( $n = 1$ ), COPD worsening ( $n = 4$ ) or infection ( $n = 4$ ), all of which should have served as an indicator that healthcare intervention was necessary.

As previously noted, all participants were able to identify a change in their baseline COPD status, but not all participants sought healthcare in a timely manner. The average treatment delay time was seven days from the onset of symptoms. In contrast to the urgent treatment seeking behaviors described previously, a “ride it out” or waiting to see if the illness resolves on its own approach was utilized by most ( $n = 11$ ) participants. Nine participants delayed treatment for seven days or more because they did not have a sense of urgency regarding their symptoms. This is in spite of, and in some cases due to, prior exacerbation experience. For example, one participant reported consistently delaying treatment seeking despite early recognition of

exacerbation symptoms and having a good relationship with her physician because she wanted to “give it a few days to see where it goes.” She was hospitalized 15 times in 2011 as a result of delaying care, and never quite recovered to baseline between exacerbations. Her decision to present to the emergency room is predicated on the severity of her dyspnea, and not her illness knowledge or prior experience. Another participant reported she just does not like being in the hospital so ignores her symptoms hoping they will go away and she can avoid hospitalization. Calling their primary care physician to initiate early home treatment did not occur to either participant in the above examples. Two other participants shared that they don’t call their primary care physicians when they recognize that they are having an acute exacerbation because “he can’t do anything to change it.”

One participant waited for symptoms to resolve for two weeks. She was admitted on the day she was interviewed. She explained:

I was going to wait until today to call my doctor. Usually he would put me on prednisone and antibiotics [and my symptoms would improve]. All of a sudden I got really bad last night, and scared. Going to bed, using oxygen, nothing was helping me.

Despite recognizing an impending exacerbation, and knowing that she typically needs medications to improve her symptom, this participant delayed calling her physician because she was waiting for her regularly scheduled appointment. When further probed about this, she explained that she did not “want to be a bother.”

Two participants described finally seeking treatment after having an especially difficult sleepless night, thinking they may not even survive the night. “It was hard to breathe. I was lying in bed waiting to check out. I couldn’t even make it to the bathroom, I was coughing and so short of breath. It was a horrible feeling.”

In a unique situation, one participant reported riding it out because his only child was getting married, and he wanted to walk her down the aisle. However, he also admitted to riding it out on prior occasions due to pure stubbornness. When he does seek healthcare it is always at his daughter's insistence.

Another aspect of this subtheme includes wanting to continue with life as usual. One participant who runs her own business describes wanting to manage her treatment on her own, despite her husband's urging to call her physician. She insisted on continuing to run her own errands, keep her appointments, and entertain relatives despite her symptom progression. She continued like this until her dyspnea was beyond control despite self-treatment, upon which she saw her physician who immediately admitted her.

I wasn't getting any air but I paid no attention to it. My husband suggested I better go to the doctor because something [was] wrong. He told me to call on Monday, I called on Wednesday and got an appointment for Thursday. When I saw...my primary doctor...he said you are going straight to the [hospital].

One participant with severe COPD described delaying calling her healthcare practitioner despite significant symptoms and distress because she wanted to cook thanksgiving dinner "as stupid as that sounds." Even her family's concern was not enough to change her mind.

A particularly independent participant discussed trying the "riding it out" strategy before seeking healthcare advice stating, "I just hoped I could ride it out, but it reaches a point where it progresses and...it's beyond me to stop [it]." She describes herself as being a very active person and not wanting to give in to illness, stating:

I'm apt to ignore it (symptoms) until it gets to a point where I can't walk from the kitchen to the dining room without having trouble breathing. I don't like being sick, I don't like

being inactive, not producing, not seeing people, not doing things. I'm not happy here (hospital), which is normal. I don't want to give into to it because it's something then I don't have control over.

When she reaches the point where she can't control her symptoms with self-help strategies, she goes to her pulmonologist's office to get "medication samples" but not necessarily for an office visit. She proceeds to the emergency room for treatment when her dyspnea becomes "unbearable."

Resistance to friend and family encouragement to seek healthcare in spite of significant symptoms was noted in a single woman's description of events. As she describes:

Sunday I went out with my friends. I was so cold [and not feeling well]. I shouldn't have gone. They (friends) wanted to call the medics. I went into the ladies room and the woman there wanted to call the medics. I said no. I wanted to go home. I was going to call my doctor today, but I had to call the ambulance last night.

During the interview it was revealed that she prefers to see her physician and be treated at home with steroids and antibiotics. She tends to wait until scheduled appointments rather than calling when she has a change in her COPD symptoms, not wanting to bother healthcare personnel on holidays and weekends. One other participant reported not wanting to seek healthcare on the weekend, but it was because she did not want to see the physician on call. She prefers to see her own physician who understands her complex medical history and the treatment protocol that works for her. In all, seven participants resisted recommendations from family and friends to seek treatment earlier. Resistance was also evident in three participants refusal to call an ambulance for transport to the hospital despite the severity of their respiratory distress.

One participant, a current smoker, suggested that her embarrassment over her continued

smoking may have contributed to her riding it out. She discussed feeling that as a smoker she was stigmatized, and wished she could overcome her “addiction.” She felt that as a smoker she was treated differently.

Participants who chose to ride it out used a variety of self-management measures as they attempted to manage symptoms, resolve their illness and avoid emergency room visits, hospitalizations and health care expenses. The participants who expressed trying to avoid engaging with the healthcare system ( $n = 5$ ) did not describe having a prior negative experiences with emergency room utilization or hospital admission. They “just didn’t like being there.” However, the cost of hospitalization was a concern for a single participant. During a previous non-COPD related hospital admissions she was uninsured and incurred rather large out of pocket expenses that drained her financial resources. Although she has subsequently acquired health insurance, she has ongoing concerns regarding co-payments and other non-insured expenses potential taxing her family resources.

Participants described employing the following self-management measures: activity modification ( $n=14$ ), rest ( $n=12$ ), rescue inhaler use ( $n=9$ ), cold medications ( $n=8$ ), breathing exercises ( $n=4$ ), special positioning ( $n=4$ ), nebulizer use ( $n=2$ ), oxygen use ( $n=2$ ), relaxation techniques ( $n=2$ ), initiation a physician prescribed action plan of antibiotics and steroids ( $n=1$ ) warm showers ( $n=1$ ) and hope ( $n = 4$ ). Although these actions did provide some subjective relief of symptoms, they were not successful in averting the onset of exacerbation or subsequent need for hospitalization. Many participants reported repeatedly responding to COPD baseline changes with a “ride it out” approach despite lack of success in avoiding exacerbations and its consequences with this behavior on prior occasions.

**Not in charge anymore**

The subtheme *not in charge anymore* is a subtheme related of the reacting to change component of the main theme. It represents the participant's personal experiences regarding the impact of COPD on their lives, and how acute exacerbations compound this negative impact on their physical health and emotional well-being. What they described in essence was an overwhelming loss of control, especially when they were feeling breathless due to an exacerbation event. Study participants used strong descriptors such as frustrating, frightening, limiting, discouraging and powerless in describing this phenomena.

The perceived loss of control over their illness and the effect that these participants experienced during an acute COPD exacerbation is clearly articulated in the following excerpt from one participant interview: "Most fears come with losing control, feeling like you are not in charge anymore." All participants expressed distress over losing control of their symptoms, and the impact it had on their life activities. Of course this distress is common in COPD, however it is potentiated during an acute exacerbation when symptoms are less easily controlled and physical activity is quite impacted. One participant described the burden of symptoms on her sense of control stating, "When I can't breathe, needless to say I can't do anything. You know it makes you down." She went on to say, "I have no control over it, you know, it's (exacerbations) part of my life now and it's no fun." This is true not only during the exacerbation, but for an extended length of time following exacerbation. As one participant explained "after an [exacerbation] you are down for three weeks really sick, and then several more weeks trying to get back to where you were before." The lingering effects of exacerbation is again described by another participant who has been suffering frequent, repeated exacerbations, stating his recovery "timeline is different". It (baseline) doesn't seem to come back. I haven't come back from last summer." This has resulted in a significant alteration in his lifestyle, inhibiting social activities



and modifying his role function within his family.

Not being able to manage symptoms, especially shortness of breath, was most distressing for participants. As one individual stated, “I had no control, I used my inhaler [several] times and it didn’t work.” Further adding, “when you can’t breathe there’s nothing you can do about it and it’s scary.” Another participant compared her escalating, uncontrollable symptoms to “a train running down the tracks out of control.” Lack of control over symptom management during an exacerbation is richly described in the following quote:

I was getting short of breath...I went and laid down. I switched body positions to get a good breath. I fell asleep and woke up and it was worse. I put on a fan and let it hit me in the face. If I had to use the bathroom it was like taking a chance of [passing out]. I was afraid to use any energy. It’s scary when you can’t control something.

The burden of not being able to control symptoms during an exacerbation is reiterated by another participant in the following:

If I like was laying in bed and I had to get up to go to the bathroom it would literally take me. I would get up and I would go into a coughing fit if I moved too much or walked from here to there...it was out of control. I would have to stop and try to breathe and get all the junk that’s in there out and do that until I finally make it where I have to go. That was the process of one place to another.

Many participants also had concerns about becoming a burden to their family as they began to recover less completely, or suffered frequent exacerbations. One participant was particularly remorseful about having smoked and that now her children were going to have to watch her die, as she had watched her father succumb to the complications of COPD as a result of smoking. “I do want to live, I don’t want my children to go through what I went through with

my father, to see that.” This topic was painful for her, and she began to cry as she discussed her father’s death, her smoking habit, and fear of her own mortality as a consequence of smoking.

A male participant spoke about his lungs and health slowly deteriorating from recurrent exacerbations and as a result never fully recovering from exacerbations anymore. He spoke of beginning to put his affairs in order, preparing a will, solidifying finances and transferring his role as head of household and caregiver to his wife. This transfer of caregiving role has been especially difficult for him, as he felt strongly it was his duty to take care of his family. A female participant also discussed getting things in order and being distressed over giving up her caregiver role: "I'm trying to get everybody in order just in case. It's frustrating because I was always the one people went to." Again, this role change was difficult:

I had to get off my high horse. I’m a general. I hate getting helped; I like to [be the one giving help], I would ignore my symptoms [and proceed with life as usual]. Getting use to change is the hardest part. I almost died [because of it].

The impact of physical performance during, and for a period of time after, an exacerbation was discussed by male (n=3) and female (n=3) participants equally, but was more elaborately described by male participants. One male participant’s description details this decline:

I’ve been unable to do much physical work at all without my heart racing and breathing hard. How pathetic...I can’t go out and cut brush on a piece of land. I can barely get down the stairs and bring up a load of laundry. It’s very restrictive...

Another male participant highlighted the impact of physical decline on his job performance stating, “I noticed my coworkers starting to pick up the slack.” And finally, the impact of physical decline on his role in the family, and his ability to keep them safe is prominent in this male participant’s quote:

The kids can't say to me watch the little ones while I run in the store, watch them with the pool, watch them when their swimming. I can't do that alone. I have the fear that [I can't go and catch them before they fall]. I can make the initial try by won't finish so that really, really bothers me.

Female participants also described their decline in physical function, but also described a willingness to modify their physical intensity to manage symptoms similar to the following example by one participant:

Toward the end I may slow down and do more deskwork...rather than bounce around outside. I'm a very active person but when this (exacerbation) hits me...

### **My last day**

The final subtheme, also related to reacting to change is my last day. The fear of dying during the peak acuity of their acute exacerbation episode was described by 64% of the participants. They described the panic, distress and feeling of suffocation that they experienced at the pivotal point when they finally decided it was time to seek treatment. A few participants expressed that they had waited too long, and were afraid they were not going to get professional help in time.

Nine participants described feeling as if it was their "last day" because their symptoms were so severe at the moment they sought healthcare. As one participant shared: "I honestly thought it was going to be my last day. Nobody wants it to be their last day." This subtheme was especially evident in descriptions by patients who had a sudden onset of dyspnea requiring immediate healthcare assistance. The following recollection illuminates the panic and distress experienced as a result of breathlessness: "trying to gasp for air and I don't have it there, you see that's the worse, trying to get air and you can't."

Other participants ( $n = 2$ ) discussed a fear of death and dying that has climaxed over the years as their disease has worsened, and their exacerbations become more frequent. As one participant who has experienced frequent, prolonged exacerbations in the last year explains:

I got a little more frightened this time than in the last 10 years. I didn't seem to be able to control it as quickly and thought it was going to get the best of me. Of course then you are concerned about your family coming in and [finding you dead]. You have to worry about them.

Another participant who has experienced several exacerbations over several years stated

I'm going to have a cardiac arrest and die, that's the first thing that crosses my mind. You know you're gasping for air and it's so frightening and that's why I...think that this is one that's going to take me one day-cardiac arrest.

Other participants ( $n = 4$ ) described their fear more vaguely stating "I thought I wasn't going to make it through the night" and "I thought it was going to end, it's always bad when you can't breathe."

For many, a conscious delay in treatment seeking preceded ( $n = 7$ ) the escalation of their symptoms. Participants recognized that by delaying treatment seeking, the acuity of their illness built to a severity level that became uncontrollable and frightening. One participant shared that if his daughter had not insisted he get care when he did that he "might have passed out or something." Recognition of personal responsibility for the severity of their current health crisis is embodied in the following exemplar:

I was {afraid} that it was going to end. I thought I was gonna not breathe at all. You know it got worse and worse and even when they were bringing me in, in my mind I was saying it, I'm going to die and they (medical personnel) don't even have enough time to

change this. I thought it was too late

One participant, who insisted on seeing her primary care physician instead of going to, emergency services for her severe symptoms “because he’s my doctor and that’s his job”, explained:

While I was waiting I thought I was not going to make it, like 99 check out time, and he saw me coming down the hall and he came over and said ‘you need to be in the hospital, you’re bad’. I agreed and went to the hospital.

The participant further shared that she had a similar “bad episode” several years prior. However, despite her prior experience, severity of symptoms, and fear that death was imminent, she insisted on seeing her primary care physician for treatment instead of engaging emergency medical services.

For two participants who did not express a fear of dying, it was a fear of requiring endotracheal intubation and ventilation that was articulated. This fear was based on prior experience with severe exacerbation that necessitated this treatment.

### Summary

Five males and nine females, age 49-87, with moderate to severe COPD participated in this qualitative descriptive study exploring awareness of prodromal symptoms, recognition of symptom patterns and treatment delay during acute exacerbation of COPD. All participants were hospitalized in community hospitals in Southeastern Massachusetts.

In summary, participant awareness of prodromal symptoms included noticing new symptoms such as palpitations, sinusitis, headache, fatigue and cold symptoms. These symptoms were different from their usual day-to-day COPD symptoms. Common cold symptoms were the most prevalent (n=8), however participants described fatigue as being the most bothersome

because of the impact it had on modifying their activities. Seventy-eight percent ( $n = 11$ ) of participants recalled having prodromal symptoms in the days preceding their exacerbation, but most did not identify their symptoms as a prodrome of COPD exacerbation.

Thirteen participants (93%) recognized their unique exacerbation pattern that recurred with exacerbation event. For some, conscious awareness of their symptoms as a pattern evolved only during the course of the study interview. The most prevalent (57%) exacerbation pattern in this sample was Anthonisen Type 3, the combination of dyspnea with a minor symptom such as cough or wheeze. Anthonisen Type 2 exacerbation, increased dyspnea and sputum, was experienced by 36% of participants, and only one participant experience a Type 1 exacerbation, increase in dyspnea, sputum production and sputum purulence. For many participants, the recognition of their exacerbation symptoms, or pattern of symptoms, alerted them to an impending exacerbation, and precipitated the initiation of self-management behaviors. For others, the symptom onset was so abrupt, or so severe that healthcare was sought immediately.

Finally, treatment delay (a delay in seeking care from the time of exacerbation symptom onset until initial contact with healthcare) was experienced by most ( $n = 11$ ) participant. Three participants presented for healthcare within 2-48 hours of their initial symptom onset because of abruptness of the onset of their symptoms (dyspnea), or the sudden worsening of their dyspnea. However 79% of participants delayed seeking treatment between three days and two weeks. Mean delay was seven days (SD 4.96). During this time, participants initiated self-management behaviors that included activity modification, rest, inhaler use, cold medications, breathing exercise, positioning, nebulizer use, oxygen use, relaxation techniques, action plans, warm showers and hope. The primary reason for delay was reported to be waiting to see if the illness resolved on its own. Many psychosocial factors contributed to participants engaging this

management approach. The physical, social and emotional consequences of COPD exacerbations are also richly described as well as feelings of loss of control over one's life, and fear of death during an exacerbation event.

## Chapter V

### **Discussion**

#### **Introduction**

The purpose of this qualitative descriptive dissertation study was to explore the COPD exacerbation experience. A primary focus was to investigate prodromal symptom awareness, describe symptom pattern recognition, and identify factors that delayed treatment seeking. This topic is important because the incidence of COPD is steadily increasing, and COPD exacerbations represent a significant physical, psychological and economic burden for patients and the healthcare system. Early recognition and treatment of exacerbation is important to decrease this burden. Little is known about how individuals recognize and respond to early signs of impending exacerbation. The study's major findings will be discussed in relationship to Leventhal's common sense model and the empirical literature reviewed for this study. The major findings include: participant awareness of an illness prodrome that precedes exacerbation onset, identification of a recurring exacerbation pattern, descriptions of psychosocial factors that contributed to treatment seeking delay and details of fears and concerns that arise during the exacerbation event. This information will add to the currently growing body of knowledge regarding the COPD exacerbation experience. This chapter will also discuss the study limitations and recommendations for future research, practice and health policy.

#### **Theoretical Framework**

The commonsense model (Leventhal, Meyer & Nerenz, 1980) undergirded this study, which focused on exploring symptom recognition and treatment delay during an acute exacerbation of COPD. This model was useful in developing the interview guide, directing probes and analyzing the data. In chronic illnesses such as COPD, patients experience occasional changes in their



health status illness, or exacerbations, that require patients to immediately process and respond to their health change. The symptoms of COPD exacerbations engage perceptual, cognitive and emotional processes. Leventhal's model provided insight for understanding how individuals experiencing acute exacerbation of COPD integrate these processes to recognize, respond and react to symptoms within the context of their individual experience. Through use of the model, it became clear how prior experience and psychosocial factors influenced each participants coping behaviors, self-management of treatment seeking actions and emotional appraisal of their illness situation.

### **Prodrome**

This study's findings suggest that patients with COPD experience, and are aware of, an illness prodrome prior to the onset of acute exacerbation. These symptoms are different from typical day-to-day symptom variations and more subtle than usual exacerbation symptoms. The phenomenon of a prodromal period was identified in two longitudinal cohort studies conducted by Aaron et al. (2012) and Seemungal et al. (2000). The importance of understanding this phase in relationship to exacerbation onset is seen as an important opportunity for initiating early treatment (Wilkinson et al., 2004). Prodrome characteristics are also helpful in determining the etiology (viral vs. bacterial) of exacerbation triggers, and guiding appropriate therapy (Aaron et al. 2012). In both cohort studies, subjects experienced worsening dyspnea, cold symptoms, sore throat and cough in the days prior to exacerbation onset. These symptoms were identified through examination of the subjects' daily symptom diary recordings. It is not clear if the subjects who completed the symptom diary cards were aware that their symptoms were worse or different from their baseline, or if they associated the symptoms with an exacerbation prodrome. All participants in the current study self-reported the presence of the same prodromal symptoms

described by Aaron et al. (2012) and Seemungal et al, (2000). Additionally, in the current study fatigue was reported as a significant prodromal symptom.

The data analyzed in this study agrees with Aaron's et al. findings (2012) that prodromal symptoms are experienced regardless of whether the exacerbation has a sudden or gradual onset. In contrast, Kessler et al. (2006) reported that 32.8% of the participants in a similar study had no recognizable warning sign prior to exacerbation. Most participants in the current study were unfamiliar with the phenomenon of an exacerbation prodrome, and therefore did not link the symptoms to imminent exacerbation. This represents a missed opportunity for early treatment to avert exacerbation and its negative consequences. However, the finding that all participants in the present study were aware of their prodromal symptoms, even if retrospectively, holds promise for developing early recognition skills and initiating early treatment.

### *Fatigue*

Fatigue has been reported as a common symptom in COPD (Baghai-Ravary et al., 2009, Gift & Shepard, 1999, Theander & Unosson, 2004) as well as a consequence of exacerbation (Baghai-Ravary et al., 2009; Rabe et al. 2007), however the finding of fatigue as a significant indicator in the prodromal period has not been previously reported. Kessler et al. (2006) discussed fatigue as a warning sign that occurred in 10% ( $n = 13$ ) of participants at exacerbation onset, but this report did not discuss a prodromal period. In the present study, bothersome fatigue was reported by 57% of participants. The experience of fatigue in COPD has been related to increased dyspnea (Baghai-Ravary et al., 2009, Gift & Shepard, 1999. During COPD exacerbation, Baghai-Ravary et al. (2008) also found that fatigue increased considerably, peaking three to four days after exacerbation onset. This increase in fatigue was also associated with increased depression.

COPD is an inflammatory disease, and recently Al-shair et al. (2011) reported a possible association between systemic inflammation and symptoms of fatigue in stable patients with moderate COPD. One might hypothesize that the presentation of fatigue in the prodromal period may also be linked to an increase in circulating inflammatory factors prior to exacerbation onset.

### **Exacerbation Symptom Patterns**

The current study findings demonstrated that patients experiencing exacerbation of COPD have an individual pattern of exacerbation symptoms that recurs with each exacerbation event (Kessler et al., 2006). Similar to novel findings from a prospective cohort study by Aaron et al. (2012), two distinct exacerbation presentations were reported by participants in this study: sudden onset and gradual onset. Sudden onset exacerbations were marked by a brief (hours) period of fatigue and increased dyspnea followed by a sharp onset of intractable dyspnea that was frightening and precipitated urgent care-seeking. Three participants (21%) experienced a sudden onset type exacerbation as compared to 55% of subjects as reported by Aaron et al. (2012). Gradual onset exacerbation was preceded by a two to seven day prodrome of symptoms. In the current study 79% of participants experienced a gradual-onset exacerbation compared to 45% of subjects in the cohort study. The difference in sample size between this study ( $N = 14$ ) and the Aaron et al. (2012) study ( $N = 1995$ ) may account for some of the findings.

### **Treatment delay**

To date, there is paucity of research literature specific to treatment delay in COPD. Participants in this study sought treatment for their exacerbation based on the severity of their symptoms, with participants experiencing sudden, severe dyspnea presenting earliest for treatment. The severity of symptoms in these individuals precipitated a sense of urgency regarding their situation. Participants who experienced a more insidious exacerbation onset

waited to see how their illness progressed before seeking treatment, and presented only when symptoms were no longer tolerable. Other qualitative studies have reported the same relationship between illness severity and treatment seeking behavior (Adams et al., 2006; Russell et al., 1998). Adams et al. (2006) cited poor symptom recognition and attribution as the reason for delay by participants in their study. In the present study, symptom recognition was not a factor, however unawareness of the relationship between prodromal symptoms and exacerbation onset was a factor for many participants. Psychosocial factors such as social commitments, not wanting to bother providers, patient-provider relationships, avoidance of hospitalization and stigmatization also contributed to delay. The most significant of these factors were patient-provider relationship and stigma.

#### *Patient-Provider relationship*

According to Fox and Chesia (2008) patient-provider relationships that includes good communication, continuity among providers and recognition of patient individuality and self-management abilities were the most satisfying for participants. Conversely, participants who did not feel understood or respected by their provider(s) became insecure and untrusting of them. This is consistent with the current study's findings, which demonstrated that participants delayed care because they (a) did not want to bother their provider, (b) believed that their provider could not help them or (c) did not want to see the physician on call. Instead these participants delayed care and presented to the emergency room for care only when they could no longer tolerate their symptoms. In contrast, several participants who reported having a good relationship with their provider believed their provider understood their individual treatment needs during exacerbation and were supportive. These participants called, or presented to their provider for advice prior to presenting to the emergency room.

## *Stigma*

According to Earnshaw and Quinn (2011) patients with chronic illness may experience internalized, experienced or anticipated stigma within the context of healthcare interactions. Reduced healthcare access and quality of life are potential consequences of stigmatization. Individuals who smoke are stigmatized by societies attitudes towards smoking and may feel shame and guilt about their smoking behavior (Earnshaw & Quinn, 2011; Halding, Heggdal & Wahl, 2010). These patients internalize those negative beliefs and subsequently may anticipate stigmatization in healthcare interactions (Earnshaw & Quinn, 2011). Three participants in the present study who delayed treatment continued to smoke, however only one of these participants expressed concerns over stigmatization related to their smoking behavior. This topic was not addressed with the other participants, as they had been interviewed prior to this topic emerging.

Stigmatization occurs when a patient perceives that healthcare workers blame him/her for his/her illness, or that health care workers are frustrated with him/her (Earnshaw & Quinn, 2011). Patients with chronic illness who require frequent hospitalizations to manage their illness are often labeled as “frequent-fliers” in healthcare settings. One participant did share that her decision to delay treatment was related to feelings of being stigmatized by the emergency room staff related to her frequent visits. She shared this during a member check interview. One may postulate that she felt comfortable discussing this out of the physical context of the healthcare environment. It is possible other participants may have had similar experiences, but this was not explored in the interviews. Although only two participants explicitly discussed stigma, this is a major finding as it influences quality healthcare interactions. In general, research focusing on the stigma experienced by individuals with COPD during healthcare interactions is sparse.

## **Emotional reactions**

Participants discussed the overwhelming loss of control they experience during an acute exacerbation, as well as their fear of dying at the moment that their exacerbation peaked and dyspnea became intolerable. Participants described feeling frightened, frustrated, discouraged and powerless as they lost control over their symptoms, their illness and their life during these illness events. Two major findings in this domain were fear of death, and discussion of suicide.

### *Depression and suicide risk*

Findings that 21% ( $n=3$ ) of participants had symptoms suggestive of depression are consistent with a large observational study (Schneider, Jick, Bothner and Meier, 2010) where the prevalence of depression was 23.1% among individuals with COPD. The three participants with depressive symptoms were women, which is consistent with other findings that women are twice as likely as men to experience depression (Laurin et al., 2007). In a smaller prospective cohort study by Regvat, Vegnuti, Kosnik and Suskovic (2011), the prevalence of depression during hospitalization for exacerbation of COPD was 42%. According to Jennings, DiGiovine, Obeid and Frank (2009), depressed individuals are 2.8 times more likely to experience exacerbation than non-depressed individuals. It is also important to note that depression scores worsen during exacerbation, with the greatest increase in those with lower levels of depression at baseline (Quint et al, 1998). Depression is also associated with alteration in motivation and cognition and feelings of hopelessness and powerlessness (Dowson et al., 2004). Consequently, illness self-management and treatment-seeking behaviors may be impaired in depressed individuals.

The three participants who demonstrated depressive symptoms in the present study were being treated for depression prior to admission. It is not known if there was a change in these participants baseline depression level as a result of the current exacerbation, however one

participant did discuss having thoughts of suicide after the current exacerbation onset and another participant was initially placed on suicide precautions on admission. These findings suggest a rise in depression acuity during exacerbation as noted by Regvat et al. (2011) and Quint et al., (1998). A search of the literature did not uncover any studies specific to suicide risk and COPD.

All participants in this study were screened for depression and suicide risk on admission according to the institutional policy, however screening practices in the larger population of patients experiencing exacerbation of COPD is not known. The current and past research findings suggests that depression screening for all individuals experiencing exacerbation of COPD needs to be a routine practice across all settings.

#### *Fear of death*

Fear of death during the current exacerbation was discussed by 64% of participants in this study. The panic they experienced as they felt they were suffocating and taking their last breath was vividly described. Six participants had delayed seeking treatment until this pivotal point, and many of them took responsibility for reaching this frightening climax before calling for help. In an observational study of COPD exacerbations, Kessler et al. (2006) found that 12% of participants feared dying and 9.6% of participants feared suffocating during exacerbation. Only one study regarding death fears during acute exacerbation of COPD was found for comparison. Bailey's (2001) narrative analysis of 10 patient-family-nurse dyads describes two distinct death fear experiences: near-death, which involves patient resuscitation, and shadow of death, where the patient fears death as a consequence of the perceived seriousness of their dyspnea. The death fears reported by participants in the current study are consistent with the near-death narrative described by Bailey (2001), however whether treatment delay was a factor in the Bailey

(2001 study is not known. How much the emotional overlay of regret related to treatment delay contributed to distress in this study is also not known.

### **Research Implications**

Findings from the current study suggest that research is needed to address: cognitive dysfunction in COPD, fatigue as a prodromal symptom, stigmatization during health care interactions and efficacy of nurse-led self-management programs for COPD. This research is important to add to the knowledge base of COPD and to guide practice and policy development.

Current research suggests that deficits in cognitive function are associated with chronic illnesses in which hypoxemia is a feature such as COPD (Dodd et al., 2010; Kapstein et al., 2009). The cognitive dysfunction in COPD is manifested as impaired decision-making, memory, recognition and executive functioning, which may contribute to poor symptom recognition (Dodd et al., 2010). Depression also impacts cognition (Dawson et al., 2006). As chronic illness self-management is increasingly recommended, the effect of COPD on learning and self-management behavior needs to be investigated to ensure patients have the requisite skills to effectively self-manage their disease and make the necessary judgment to seek treatment when appropriate. Additional research is needed to establish the prevalence of cognitive impairment in COPD, identify correlating factors, and determine the impact of deficits on symptom recognition and treatment decision-making.

Despite earlier evidence to the contrary (Monninkhof et al., 2003), a recent Cochrane Review (Effing et al., 2007) and study (Schofield et al., 2006) indicated that nurse-led self-management education, interventions and programs may be beneficial in improving outcomes for individuals with COPD. Successful management of COPD requires a chronic care model approach to care that is patient-centered, empowering, provides competency-based self-



management education and decision-making support. The success of this model is predicated on the successful development of the nurse-patient relationship, shared knowledge of the patient's illness experience and collaboration between all health team members (Corsello & Tinkelman, 2008). In other chronic diseases, such as heart failure, nurse-led self-management programs have been successful in supporting patient self-management, reducing hospitalizations and improving patient and healthcare outcomes. Success has been demonstrated in clinic delivered (Smeulders et al., 2010), telephone delivered (Brandon, Schuessler, Ellison & Lazenby, 2009) and home monitoring support (Manning, 2011). The implementation of a nurse-led self-management program for the management of COPD has implications for improving the care of individuals with COPD, however the research supporting implementation of this intervention is limited. Additional research is needed to identify essential program components, determine the most appropriate delivery model and assess the long-term effectiveness of a nurse-led self-management program for COPD.

Stigma was identified as a potential barrier for healthcare access and quality care. Research is needed to understand more about how stigma affects access to prompt care for persons with COPD. Additionally we need to understand how health care provider attitudes affect self-management and prompt treatment of COPD exacerbations.

As a result of the current study's findings, it appears that strategies to improve prodromal and exacerbation symptom recognition is a priority to improve early detection and treatment. Symptom diaries have been used in large longitudinal cohort studies investigating exacerbation prevalence and typologies. In the cohort studies, the diaries were used as a data collection tool rather than a self-management tool. Symptom diaries have improved symptom recognition and self-care in individuals with heart failure (White, Howie-Esquivel & Caldwell, 2010) when

participants adhered to daily symptom recording and sought prompt healthcare attention in response to symptom change. The efficacy of a daily symptom diary to improve exacerbation recognition and treatment seeking in individuals with COPD needs to be investigated.

Adherence to diary use, accuracy of data interpretation and appropriateness of care seeking in response to symptom change in this population needs to be determined.

Findings in this study implicate fatigue as a prodromal symptom of acute exacerbation. Fatigue as a co-morbid condition in COPD, and fatigue changes related to dyspnea intensity during baseline COPD and exacerbation have been well documented. However, further research is needed to specifically measure changes in fatigue intensity in the time period just prior to exacerbation onset, and to establish a clear association between fatigue and impending exacerbation.

### **Practice Implications**

Practice implications from this study include: developing patient-provider partnerships and improving patient teaching for patients with COPD. Data analysis revealed that participants who had confidence in their healthcare provider, and who felt comfortable contacting them during illness were more likely to call the office for advice than to utilize emergency services. Given the physical and emotional complexity of this chronic illness, as well as the economic burden, it is important for healthcare professionals to develop collaborative partnerships with patients to improve health outcomes on all levels. Healthcare workers need to be sensitive to each individual's perspective and goals regarding their illness management. Healthcare personnel also need to engage in self-reflection and examine their own biases regarding individuals with COPD to avoid inadvertently stigmatizing patients.

Nurses caring for patients with COPD need to provide patient education that will support and improve patient self-management. In 2008, the Institute for Healthcare Improvement (IHI) (Nielsen et al., 2008) instituted a campaign to improve the care of patients with heart failure. Important components of this program are strategies to improve the impact of patient education. Guidelines to improve nursing knowledge of heart failure management and core measures to be addressed during patient teaching are outlined. A similar strategy, based on research evidence as outlined in the prior section, should be considered to improve COPD patient education and self-management. The Joint Commission's (JCAHO) Management of the Patient with COPD Certification Program states that the most successful elements of a COPD management program includes competency-based COPD education for nurses as well as patients. Although these recommendations are targeted toward outpatient and ambulatory care settings, they have important implications for acute care nurses who manage patients during acute exacerbations of COPD.

Findings from this study suggest that regardless of setting, COPD exacerbation teaching should include assisting patients to recognize their individual prodromal symptoms and to understand their importance as a warning sign of impending exacerbation. The onset, or worsening, of fatigue in the prodromal period in more than 50% of our participants is also an important finding for patient teaching. Patients should be instructed to interpret this onset or change as a prodromal symptom. Since it is possible that patients may not experience (Kessler et al., 2006) or recognize early signs of impending exacerbation, patients also need to be assisted to recognize their individual exacerbation symptom pattern and be encouraged to seek treatment immediately upon presentation of these symptoms.

## **Policy**

The main policy recommendation is support for the development of COPD management programs to improve the quality of care for patients and reduce the economic burden of COPD related hospitalizations on the health care system. The Institute of Medicine Committee on the Quality of Health Care in America has recommended disease management programs, based on evidence based-guideline, for patient-centered, coordinated management of chronic diseases such as COPD. Educational programs for patients and providers, and supported self-management are the cornerstones of disease management programs.

COPD exacerbation is one of the leading causes of hospitalization for older adults (Wier, 2008). The high rate of hospitalization in this population suggests that patients with COPD are not adequately managing and responding to their symptoms. This is confirmed by the substantial treatment-delay by the majority of participants experiencing an exacerbation in this study. In a national survey, only 25% of respondents believed they had the information they needed to successfully manage their disease (Barr et al., 2005). The present study uncovered knowledge gaps regarding the importance of prodromal symptom and the presence of recurring exacerbation symptom patterns. This is a missed opportunity for early treatment, avoidance of hospitalization, and reduced physical and economic consequences of exacerbation.

The literature suggests that empowering patients with the knowledge, skills and support to manage their disease is the best approach to improving the quality of care and quality of life of these individuals (Bourbeau et al., 2003; Cicutto, Brooks & Henderson, 2004). Self-management with supported decision-making is a health care intervention that empowers patients to partner with their providers in managing their health and ensuring appropriate health-care actions are taken (Embrey, 2006). The goals of COPD self-management programs are to

address physical and emotional symptoms and improve patient and financial outcomes. Recommended program components include an emphasis on patient education and self-management skills, workshops to enhance symptom recognition and self-management, population specific literature, internet support and a detailed action plan for exacerbation management (NCQA, 2009). Similar programs in Australia and the United Kingdom have been successful in decreasing hospitalization rates and emergency room visits (Adams, 2007).

The American Lung Association is currently working with state agencies to develop and designate funds for COPD programs. All stakeholders involved in the care of individuals with COPD across the continuum to advocate and support the development of quality COPD management programs that includes a pulmonary nurse specialist case-manager to support patient self-management and decision-making.

### **Limitations**

There are several limitations in this study. The small purposive sample was predominantly white (79%), female (64%) and educated (mean 13.4 years) with moderate to severe (Stage 2-3) COPD. All participants had medical insurance and lived in Southeastern Massachusetts. Therefore, results can only be interpreted in this context. These findings may not reflect the experiences of individuals in other geographic areas, or populations that are more culturally diverse, less educated and uninsured. These findings also may not represent the experience of individuals with mild (Stage 1) or very severe (Stage 4) COPD. The small sample also limited the use of statistical methods to analyze data for any associations.

Despite using a calendar to facilitate symptom recall, patients had difficulty remembering the exact day and time their prodromal and exacerbation symptoms appeared. Therefore the number of days reported for prodrome and treatment-delay length must be evaluated with

caution. The use of daily symptom diary card might have been useful for capturing these data, although studies by Bennett, Amtmann, Diehr and Patrick (2012) and Meek et al. (2001) revealed no differences when comparing memory recall of COPD symptoms to daily diary reports. Nonetheless, a symptom diary should be considered in future COPD studies to authenticate prodromal symptom duration and treatment delay time.

Participant burden was a limiting factor for at least two participants. The total procedure collection time was 40-60 minutes, depending on patient rest and hygiene needs (using bathroom). In one case, the participant became tearful when discussing her illness, requiring periods of rest and support. A second participant experienced dyspnea during the interview period necessitating that the participant rest at two separate time points. This may have precipitated premature closure of the interview by the PI, as she became concerned for the participant's well-being.

In this study the MHI-5 was administered following the participant interview. This was placed at the end to decrease participant burden prior to the interview, as demographic data and the MMSE preceded the interview procedurally. Three participants declined completing the MHI-5 when asked if they felt up to completing an additional measure. Although they reported fatigue as the reason for the decline, in all three cases visitors were arriving, or pending and that may have influenced participant participations. For participants who did complete the subscale, it is possible that illness details discussed during the interview could affect the scoring of the MHI-5, and would recommend administering before the interview in subsequent studies.

## **Conclusion**

This is the first comprehensive qualitative study on prodromal symptom awareness, symptom recognition and treatment delay in patients experiencing an acute exacerbation of

COPD. Analysis revealed that patients are aware of the presence of prodromal symptoms in the pre-exacerbation period. The onset, or worsening of fatigue was also found to be a significant prodromal indicator. Participants also recognized that they had an individual exacerbation symptom pattern. However, participants needed to be guided to awareness of their prodromal symptoms and exacerbation symptom pattern experiences. Patients also did not understand the importance of prodromal symptoms, or their relationship to exacerbation onset. These findings are important for developing patient education and support tools that facilitate early recognition and treatment of exacerbation to improve patient outcomes.

When self-management behaviors are unsuccessful, patients need to engage with healthcare providers. Factors that facilitate successful engagement must be promoted, and factors that impede engagement removed. Good patient-provider relationships are integral to empower patients, develop collaborative relationships and promote effective COPD self-management. Barriers to seeking healthcare treatment such as perceptions or experiences of stigma and co-morbid depression need to be addressed and the appropriate intervention applied.

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Appendix A



Demographic Data Sheet

Subject # \_\_\_\_\_

Date: \_\_\_\_\_

Age at interview _____	
Gender	1= Male ( ) 2= Female ( )
Marital Status	1= Single 2= Married 3= Widowed 4= Co-habiting
Race	1= White- non-Hispanic ( ) 2 = African American ( ) 3= Asian ( ) 4= Other ( ) _____
Ethnicity:	1= Portuguese 2= Hispanic 3=Other _____
Highest grade completed in school _____	
Years since diagnosed with COPD* _____	
Date of last COPD exacerbation * _____	
Number of exacerbation hospitalizations since diagnosed * _____	
Current smoker	1 = yes ( ) 2 = no ( ) 3= never smoked ( )
Date quit	_____
Number of years smoked	_____ Number packs day _____
CalculatedPack/years	_____
Smokers in home	1= yes ( ) 2= No ( )
COPD Medication List *	

**Clinical Data**

**Pulmonary Function Tests \***

FEV1	_____
FEV1/FVC %	_____

- Obtained from medical record



## Appendix B

### Interview Guide

Conceptual Area	Aim	Question	Probe
<p>Symptom Recognition</p> <p>Cognitive Representation</p>	Explore individual's perception of prodromal symptoms in the days preceding their acute exacerbation.	<p>Tell me about how you have felt in the last 2 weeks?</p> <p>What symptom(s) did you experience?</p> <p>When exactly did you first notice (x) symptom? (Use a calendar as a point of reference)</p>	<p>Did you experience: SOB, cough, sputum production or color changes, sore throat, chest tightness, fever, fatigue, sleeplessness, change in mood or nasal discharge?</p> <p>Did you feel a cold coming on? What were you doing in the days preceding these symptoms?</p> <p>What did you do on Monday? How did you feel?</p>
<p>Symptom recognition</p> <p>Cognitive Representation</p>	Describe individuals experience of patterns associated with their acute exacerbations	<p>What symptoms did you have with your last exacerbation?</p> <p>What about the exacerbation before that?</p> <p>What did you do at that time ?</p>	<p>Were they similar to the symptoms you had this week? What was similar, what was different. Do you notice a pattern here?</p> <p>Have you had x,y,z occur together before?</p> <p>Did you have to see your HCP?</p> <p>Were you ever admitted for "exacerbation of COPD" or pneumonia?</p>
<p>Illness Representation</p> <p>Cognitive and emotional Representation</p> <p>Cognitive domains</p> <p>Identity</p> <p>Time-line</p> <p>Consequences</p> <p>Cause</p> <p>Controllability</p>	Explore the impact of illness domains on illness representation and relationship to delay in treatment seeking during acute exacerbation of COPD.	<p>What did you think your symptoms meant? (identity)</p> <p>What do you think caused your exacerbation? (cause)</p> <p>How serious did you think youth illness was?</p> <p>What did you think might happen if your symptoms progressed?</p>	<p>Did you think you had a cold, flu, pneumonia? exacerbation? Do you know what that word means?</p>

Conceptual Area	Aim	Question	Probe
		<p>What are you most concerned about? (consequences)</p> <p>How long have you had this “flare up”</p> <p>“How long do you think it would last” (timeline)</p> <p>What did you do to manage your symptoms?</p> <p>How much control over your symptoms or illness did you believe you had? (Controllability)</p> <p>What made you decide to call your HCP (or come to the hospital)?</p> <p>Do you think you should have got care sooner? Why did you wait? (Treatment delay factors)</p>	<p>Did you change your medications, activity etc. to improve your symptoms?</p>