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Marnie M. Wetzstein

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EXAMINING DETERMINANTS OF PATIENT ACTIVATION IN CHRONIC
OBSTRUCTIVE PULMONARY DISEASE: A CROSS-SECTIONAL SURVEY STUDY

by

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Bachelor of Science, Carroll College/Columbia College of Nursing, 1995

A Dissertation

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

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This dissertation, submitted by Marnie M. Wetzstein in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

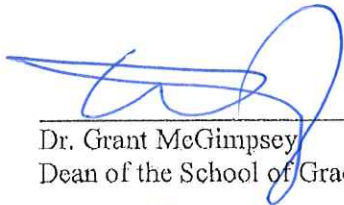
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Marnie M. Wetzstein
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ABSTRACT

Introduction: Self-management plays a central role in the treatment chronic obstructive pulmonary disease (COPD). However, the patient characteristics *necessary* for effective self-management are not understood. The skills, confidence, and knowledge to engage in chronic disease self-care, known as patient activation, may play a key role in the capacity of people to self-manage COPD. How the complex, systemic nature of COPD influences patient activation has not been explored. Therefore, the purpose of this study was to examine the relationships among patient characteristics and health outcomes as determinants of patient activation among community-dwelling adults in the U.S. with COPD. The Revised Wilson Cleary Model (Ferrans, Zerwic, Wilbur & Larson, 2005) was adapted to examine a continuum of integrated variables integral to the experience of COPD for this descriptive correlational survey study.

Methods: A random sample of 64 community-dwelling adults with COPD completed a self-report postal survey. The questionnaire was comprised of demographic questions and the Positive Affect Negative Affect Schedule, to measure individual and environmental patient characteristics, and the Quality of Life Index Pulmonary Version III, Pulmonary Functional Status and Dyspnea Questionnaire-Modified, a single question to assess general perception of health, and the Patient Activation Measure-13 (PAM) to assess health outcomes. Additionally, spirometry data was abstracted from participants' medical records. Descriptive and univariate statistics were utilized to describe and examine the unadjusted associations between patient characteristics, health outcomes and patient activation scores. Variables significantly ($p < .25$)

associated with patient activation were entered into stepwise multivariate regression models to identify independent predictors of patient activation in the sample.

Results: The participants in the study were mostly men and women in their 70s with moderate to severe COPD, having lived with the disease for over four years. The patient activation scores were high among the sample ($M = 66$, $SD = 16$), with over 70% of the sample activated at PAM Level 3 and 4 ($n = 47$, 73%). Univariate analyses revealed significant relationships between several patient characteristics (gender, positive affect, lower Body Mass Index, education level, time since diagnosis of COPD, smoking pack years, urban residence) and patient activation. Health outcome domains, such as low fatigue, good or very good general perception of health, and better perceived overall quality of life) were directly related to patient activation in the sample. The resulting statistically significant regression model ($R^2 = .488$, $Adj.R^2 = .454$, $p < .001$) contained four independent predictors explaining 45% of the variation in patient activation in the sample. Positive affect $\beta = .457$ contributed most to the model, followed by smoking pack years $\beta = .345$, overall quality of life $\beta = .264$, and female gender $\beta = -.192$.

Conclusions: Several patient characteristics and complex health outcomes underlie self-management capacity in COPD. This study revealed novel determinants of patient activation that have implications for COPD self-management science and nursing practice. Nurses are in a pivotal position to apply knowledge of patient activation to the individualized assessment and care interventions of people living with COPD. Further research is needed to explicate the unique psychosocial factors that contribute to capacity to self-manage for targeted intervention design in this population.

CHAPTER I

INTRODUCTION

More than 15 million Americans have chronic obstructive pulmonary disease (COPD), the fourth leading cause of chronic morbidity and preventable death in the United States (CDC, 2017). COPD is defined as “a preventable and treatable disease state characterized by airflow limitation that is not fully reversible...the airflow limitation is usually progressive and associated with a chronic inflammatory response of the lungs to noxious particles or gases” (Celli et al., 2015, p. e5). Often referred to as an *umbrella diagnosis*, COPD encompasses a spectrum of chronic lung diseases, including chronic bronchitis and emphysema (GOLD, 2018). These diseases are thought to be caused by long-term exposure to airway irritants, most commonly cigarette smoking, and are characterized by air flow obstruction causing debilitating shortness of breath, coughing, and fatigue (ALA, 2017; CDC, 2017). Exacerbations and development of comorbid conditions are typical in the progression of COPD and contribute to overall disease severity and mortality (Halding and Grov, 2017). The incidence of COPD is roughly equal between the genders, though in the last decade women exceed men in the numbers of both newly diagnosed and those dying from the condition (ALA, 2017; Celli et al., 2015; Pruitt, 2014).

COPD treatment plans are multifaceted with self-management intensive (Titova et al., 2017; Disler, Gallagher & Davidson, 2012). The plans require patients to monitor and manage their symptoms and mood, avoid respiratory triggers, stop smoking, adhere to medication

regimens, engage in regular physical activity, and actively maintain supportive relationships (Celli et al., 2015; Disler et al., 2012; Kaptein, Fischer & Scharloo, 2014). As COPD cannot be cured, the goals of treatment are to slow disease progression, and maintain function and quality of life (Kruis et al., 2013).

Research Problem

Evidence suggests vigilant self-management is directly associated with reduced hospital admissions, decreased perception of shortness of breath, and improved quality of life in people with COPD (Andenaes, Bentsen, Hvinden, Fagermoen & Lerdal 2014; Zwerink et al., 2014). Studies have also shown that less than one-half of patients with COPD demonstrate adherence to recommended self-management activities prescribed in their treatment plans (Bischoff et al., 2012; Bucknall et al., 2012). Further, randomized clinical trials investigating approaches to effectively teach and support patients with COPD to self-manage have yielded controversial results, including adverse events (Kaptein et al., 2014; Nici, Bontly, ZuWallack & Gross, 2014).

Though the burden of COPD has been implicated with poor adherence to treatment plans, it is highly debated in the field why self-management interventions succeed for some patients and fail for others (Bender, 2014; Titova et al., 2017). To address the disparate results of intervention trials and low treatment adherence among adults with COPD, the research community have begun to question what patient characteristics are *necessary* to become motivated and effectively engage in self-management behaviors (Nici et al., 2014). As clinicians and researchers call for individualized approaches to care tailored to the unique characteristics and strengths of individuals with COPD, knowledge of these factors is needed.

The patient's capability to self-manage this chronic disease has gained the attention of health care providers and researchers. Patient activation has emerged as a primary mechanism in

self-management processes (Moore et al., 2016) and a reliable measure of self-management capacity in chronic disease (Hibbard, Greene, Shi, Mittler & Scanlon, 2015). Patient activation reflects individual's beliefs that they have an important role to play in their health and is demonstrated through the knowledge, skills, and confidence to maintain function, respond to changes in health, and access appropriate care for their health needs (Hibbard, Stockard, Mahoney & Tusler, 2004). The Patient Activation Measure (PAM) objectively characterizes an individual's activation level on a developmental spectrum of the passive care receiver with limited self-management capacity (Level 1) to the confident, capable, and engaged self-manager (Level 4) (Hibbard et al., 2004). The higher the level of patient activation an individual has, the more likely he or she will have a sense of responsibility for their health, carry out self-care activities to maintain wellness, engage with the health care system, and achieve treatment goals, (Dixon, Hibbard & Tusler, 2009; Greene, Hibbard, Sacks, Overton & Parrotta, 2015; Mosen et al., 2007).

Despite the growing body of evidence that suggests patient activation is the most reliable indicator of a patient's ability to manage his or her chronic disease (Coventry, Fisher, Kenning, Been & Bower, 2014; Green et al., 2015; Halding & Grov, 2017), determinants and mediators of patient activation are still relatively unknown (Hibbard et al., 2015). Understanding the impact of chronic disease and healthcare practices on patient activation level has recently emerged as a focus of nursing inquiry. Several studies have attempted to identify determinants of patient activation in adults with a variety of chronic diseases. The results of these studies are broad and contrasting, preventing any consensus of the factors that may predict patient activation (Graffigna, Barello & Bonanomi, 2017). Further, most were conducted without a theoretical or conceptual framework to explain variable choice or results in a meaningful way for translation or

application in clinical practice (Bos-Touwen et al., 2015; Hibbard et al., 2015; Korpershoek et al., 2016).

The concept of patient activation has relevance in the treatment of COPD where the onus of treatment success lies in the capacity of the patient to engage in treatment plans is dependent upon self-management behaviors. Knowledge about how the complex, systemic nature of COPD affects patient activation development is lacking in the literature (Evans & Morgan, 2014; Korpershoek, 2015; Titova et al., 2017). In addition, the underlying patient characteristics supporting patient activation in the individual with COPD have not been explicated (Case et al., 2017). Nurses are pivotal in delivery of self-management education and support to people with COPD, thus knowledge of ways to promote patient activation is important to nursing practice. Examining how individual patient and disease-specific factors affect patient activation level, through the lens of an organizing conceptual framework, would inform a gap in the patient activation and COPD self-management evidence bases.

Evidence of patient activation as a predictor of chronic disease outcomes carries health policy implications for COPD care. Health care utilization rates and costs for people with a primary diagnosis of COPD are approximately twice that of age and sex-matched controls (Green et al., 2015). Preventing readmission to the hospital through self-management is a national priority for COPD care, as one in five people hospitalized for an exacerbation of COPD will require re-hospitalization within 30 days (Charlot et al., 2017; National Quality Measures Clearinghouse, 2017). Patient activation has been shown to mediate collaborative self-management programming and hospitalization rates in people with COPD, thus, patient activation may be a modifiable target in practice and policy planning efforts to reduce hospitalization and readmission for people with COPD (Charlot et al., 2017). Established

evidence shows adults with higher patient activation levels are more likely to participate in symptom monitoring and medication adherence (Hibbard & Greene, 2013, 2014; Hibbard et al., 2015), two key self-management behaviors strongly associated with decreased hospitalization and re-hospitalization for acute exacerbation of COPD (Roberts et al., 2016; Zwerink et al., 2014). Because COPD is a resource-intensive disease process imparting costly healthcare utilization burden on patients, providers, and payers (Dhamane et al., 2015), an examination of the influencing factors for patient activation in this population is warranted.

Conceptual Framework

Patient activation is a multidimensional concept yet to be examined or tested within a conceptual or theoretical framework. Therefore, a robust conceptual model that examines patient activation in the bio-behavioral context of COPD is needed to guide this study. The widely used Revised Wilson Cleary Model of Health-Related Quality of Life (Ferrans, Zerwic, Wilbur & Larson, 2005) was chosen to guide the description and examination of relationships among patient characteristics, health outcomes, and patient activation among adults with COPD.

In 1995 Wilson and Cleary (1995) proposed a model to help clinicians and researchers conceptualize and test potential relationships among health outcomes and their collective impact on overall quality of life in the setting of chronic disease. The Wilson Cleary Model of Health-related Quality of Life (Wilson & Cleary, 1995) integrated the biomedical and sociological scientific views of quality of life and proposed taxonomy of health outcome measures organized by dominant causal relationships. Five outcome levels of health in chronic disease were proposed in the model: (a) biological/physiological variables, (b) symptoms status, (c) functional status, (d) general health perceptions, and (e) overall quality of life (Wilson & Cleary, 1995). The authors proposed that these health outcomes could be linearly or reciprocally related to each

other, and may be influenced by the individual and environmental characteristics of the person living with a chronic disease (Wilson & Cleary, 1995).

In 2005 Ferrans, Zerwic, Wilbur, and Larson revised the Wilson Cleary Model (Wilson & Cleary, 1995) to explicate the conceptual definitions of individual and environmental characteristics and theoretically ground their relationships with each of the five health outcome levels of the model. Ferrans et al. (2005) asserted that the characteristics of individuals and their environment were significant and influenced all the health outcomes within the model. See Figure 1. In addition, the authors expanded the definitions of each of the health outcome levels, providing real-life examples of the outcomes and their relationships with other factors in the model in the context of nursing care situations. Their primary goal of the revision was to increase utility of this comprehensive health outcome model for guiding nursing research in chronic disease (Ferrans et al., 2005). Both versions of the model have been widely utilized in COPD health outcomes research, including examinations of general perceptions of health and overall quality of life (Guyatt et al., 2007).

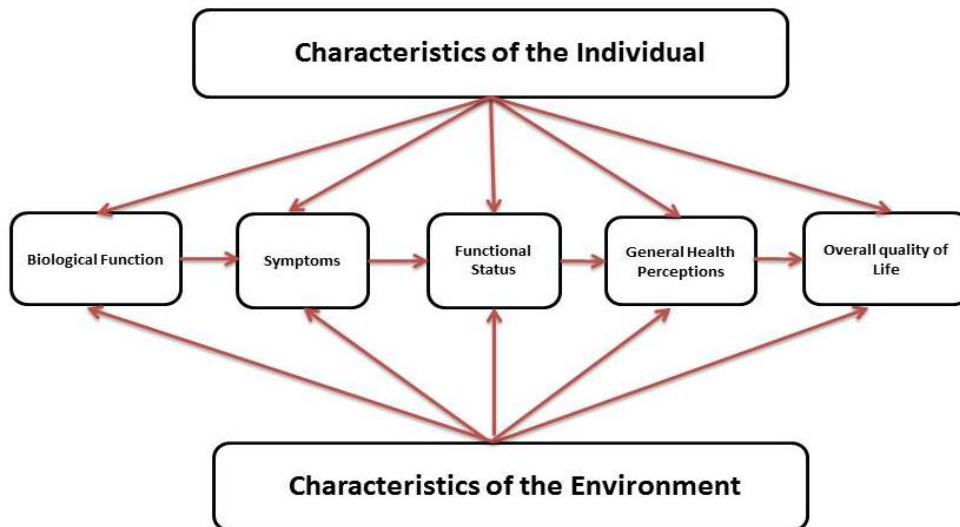


Figure 1. The Revised Wilson Cleary Model of Health-related Quality of Life. Adapted from “Conceptual model of health-related quality of life,” by C.E. Ferrans, J. Zerwic, J. Wilbur, and J. Larson, 2005, *Journal of Nursing Scholarship*, 37(4), 336-342. Copyright by C.E. Ferrans.

The Revised Wilson Cleary Model of Overall Quality of Life (Ferrans et al., 2005) organizes categories of health outcomes in chronic disease on a continuum of increasing complexity and integration. Though dominant causal associations between individual and environmental characteristics and the continuum of health outcomes are proposed, reciprocal, mediated, or integrated relationships may exist (Ferrans et al., 2005). Consistent with Wilson and Cleary (1995), Ferrans et al. (2005) assert that the model is intended to be fluid enough for guiding health outcomes inquiry as well as testing relationships among the concepts described in the model domains.

The Revised Wilson Cleary Model (Ferrans et al., 2005) afforded a fitting frame to examine potential relationships among patient characteristics, COPD-specific health outcomes, and patient activation. Patient activation and overall quality of life are modifiable, subjective, and fluid health outcomes shaped by life circumstances and health status (Ferrans, 1996; Ferrans et al., 2005; Guyatt, Feeny & Patrick, 1993; Hibbard & Green, 2013; Wilson & Cleary, 1995). Both concepts have been identified as causal influences, mediators, and predictors of health behaviors and patient outcomes in COPD (Guyatt et al., 2007; Hibbard et al., 2015; Kaptein et al., 2014). The levels of patient activation reflect a continuum of developmental capacity to apply necessary knowledge, skill, and confidence to self-manage one’s health in the setting of chronic disease (Hibbard & Mahoney, 2010). This is consistent with Wilson and Cleary’s view that measures of health can be categorized as existing on a continuum of increasing biophysical, social, and psychological complexity (Wilson & Cleary, 1995).

This study adapts the Revised Wilson Cleary Model (Ferrans et al., 2005) to include patient activation adjacent to overall quality of life on the far right of the model. Wilson and Cleary (1995) originally depicted quality of life as an end-point in the model because of the integrative complexity of the concept. Patient activation shares similar integrated biopsychosocial complexity (Hibbard & Mahoney, 2010). Based on the congruency of these conceptual descriptions, patient activation was purposefully integrated as an end point in the model. Figure 2 illustrates the theoretical continuum and adaptation of the model.

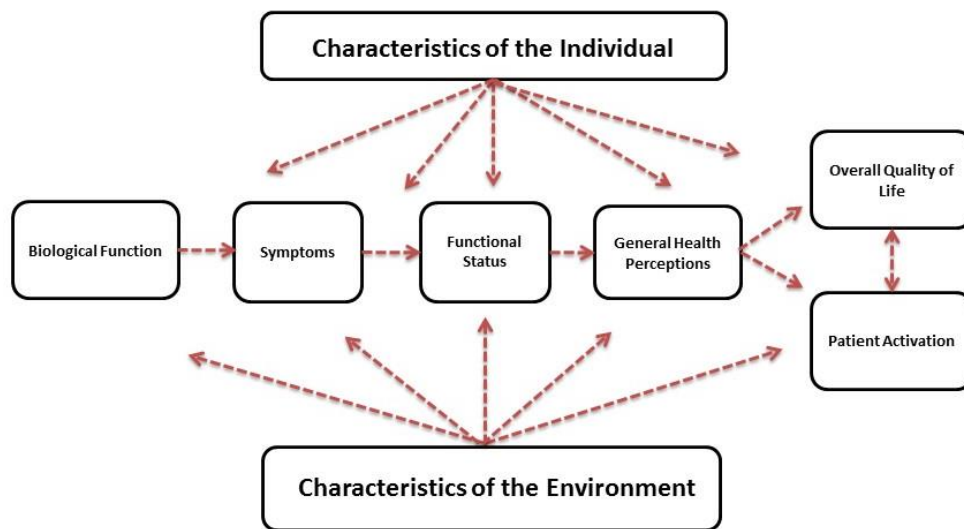


Figure 2. Revised Wilson Cleary Model of Health-related Quality of Life Adapted to Include Patient Activation. Adapted from “Conceptual model of health-related quality of life,” by C.E. Ferrans, J. Zerwic, J. Wilbur, and J. Larson, 2005, *Journal of Nursing Scholarship*, 37(4), 336-342. Copyright by C.E. Ferrans. Model adapted with permission from C.E. Ferrans.

An additional adaptation of the model was a change in the visual representation of the relationships among the health outcome domains. The model provided a framework for *examination* and *description* of relationships among relevant individual, environmental, and health outcome factors and patient activation, not testing of the model for fit. Thus, the directionality of the lines was kept consistent with the original model, reflecting the proposed

unidirectional flow of health outcomes toward the end points of overall quality of life and patient activation. Unlike the original model, the lines were depicted in a dotted format, representing a tentative relationship, to be explored in the aims of this study. The visual change is congruent with Ferrans et al. (2005) and Wilson and Cleary (1995), whose research reveals it is conceivable and probable that any arrow between the health outcomes could point in an opposite direction or both directions, reflecting the complexity of interactions between and among them.

Purpose Statement

The purpose of this study was to describe and examine the relationships among patient characteristics and health outcome factors, as conceptualized in the Revised Wilson Cleary Model (Ferrans et al., 2005) as determinants of patient activation in adults with COPD.

Specific Aims and Research Questions

The specific aims and research questions that guided this cross-sectional, quantitative study include:

1. Describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of adults in the United States with COPD.

Q1. What are the patient characteristics of the sample?

Q2. What are the health outcome factors experienced by the sample?

Q3. What is the patient activation level of the sample?

2. Examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample.

Q4. What are the presence, strength, and direction of the relationships among the patient characteristics, health outcome factors, and patient activation level in the sample?

3. Identify the independent predictors of patient activation in the sample.

Q5. Which patient characteristics and/or health outcome factors explain the greatest percentage of the variance in patient activation within the sample?

Definition of Terms

Several key terms were presented in the research questions underpinning this study.

COPD, patient activation, and the domains presented within the Revised Wilson Cleary Model (Ferrans et al., 2005) are conceptually defined in Table 1 to provide clarity of intent within the context of this study. Objective measures and empirical tools, congruent conceptually and operationally with of each of the study variables, are described in greater detail in Chapter III.

Table 1. Definition of Terms.

Term	Definition
Adults with COPD	People with a clinical diagnosis of COPD, chronic bronchitis, or emphysema. Though chronic asthma of adulthood, bronchiectasis, and alpha-1 antitrypsin deficiency are also included under the umbrella of COPD (GOLD, 2018), for the purposes of this study only the initial three diagnoses were included.
Biological function	The molecular, cellular, and whole organ system processes that support life (Ferrans et al., 2005). Operationally, biological function is defined as the measures used to assess and diagnose organ function (Wilson & Cleary, 1995). For this study, severity of COPD quantified by spirometric measure of lung function (forced expiratory volume in one second, or FEV ₁), reflected biological function.
Characteristics of the environment	The social or physical factors influencing health of the individual within their living setting (Ferrans et al., 2005). Friends, family, and caregivers represent the interpersonal and social influences of health within one's environment. The setting in which one lives, works, and engages socially also influences health outcomes (Ferrans et al., 2005). Operationally, three representative variables determine this domain: (a)

	category of residence (rural or urban), (b) marital status (single, married/committed relationship, separated/divorced, or widowed), and (c) living status (alone or with others).
Characteristics of the individual	The demographic, psychological, developmental, and biological factors that collectively influence health outcomes (Ferrans et al., 2005). For this study, the characteristics of the individual were determined through self-report of the following variables: (a) demographic measures (age, gender, race, ethnicity, formal education, earned income level, working status), (b) psychological measures (positive and negative affect as measured by the Positive Affect Negative Affect Schedule), and (c) biological measures (height and weight to calculate Body Mass Index).
Determinants	Influencing factors that decisively affect the nature or experience of a health outcome in chronic disease (Dictionary.com, 2016). Operationally, a determinant reflected an independent variable reflecting a significant relationship with the dependent variable through multivariate regression statistical analysis.
Dyspnea	The perception of labored, uncomfortable breathing (Tel, Bilgic & Zorlu, 2012). Dyspnea is a medical term synonymous with shortness of breath.
Fatigue	A multidimensional sensation of tiredness perceived as deterring one's capacity to function normally in the setting of COPD (Kapella, Larson, Patel, Covey & Berry, 2006).
Functional status	A person's ability to perform tasks in multiple domains reflecting adequate physical, social, role and emotional capacity (Ferrans et al., 2005). Functional status is operationalized as the total score of the Pulmonary Functional Status and Dyspnea Questionnaire-Modified (Lareau, Meek & Roos, 1998).
General health perceptions	A person's subjective perception of overall health status (Ferrans et al., 2005). Wilson and Cleary (1995) asserted that self-rated health was synonymous with general health perception, thus the single question from the Medical Outcomes Study SF-36 (Ware & Sherbourne, 1992) asking, "How would you rate your health? Excellent, very good, good, fair, or poor?" was utilized to operationalize this health outcome.
Health outcomes	Umbrella term referring to all patient health outcome levels (Ferrans et al., 2005) or domains (Wilson & Cleary, 1995) presented in the Revised Wilson Cleary Model of Overall Quality of Life and the original Wilson and Cleary Model of Health-related Quality of Life. In

	<p>this study, health outcomes include biological function, symptoms, functional status, general health perception, and overall quality of life, as named by Ferrans et al. (2005).</p>
Overall quality of life	<p>The subjective, multidimensional measure of well being and satisfaction of one’s life with chronic disease (Ferrans et al., 2005). For this study overall quality of life was operationalized by the total score from the Quality of Life Index Pulmonary Version III (Ferrans & Powers, 1985).</p>
Patient activation	<p>An individual’s belief she or he has an important role to play in their health, demonstrated through the knowledge, skills, and confidence to maintain function, respond to health changes, and access appropriate care for their health needs (Hibbard, et al., 2004). Patient activation was operationalized by the Patient Activation Measure-13 (Hibbard, Mahoney, Stockard & Tusler, 2005).</p>
Patient characteristics	<p>Umbrella term referring to both the characteristics of the individual and characteristics of the environment, as presented in the Revised Wilson Cleary Model of Overall Quality of Life (Ferrans et al., 2005) and the original Wilson and Cleary Model of Health-related Quality of Life (Wilson & Cleary, 1995).</p>
Self-management	<p>The medical, emotional, and role management tasks or behaviors to manage health and maintain wellness in the setting of chronic disease (Grady & Gough, 2014; Lorig & Holman, 2003).</p>
Symptoms	<p>Person’s perception of an abnormal physical, emotional, or cognitive state (Ferrans et al., 2005). Dyspnea and fatigue are the key physical symptoms relevant to COPD. Dyspnea was operationalized by the Dyspnea component subscale from the Pulmonary Functional Status and Dyspnea Questionnaire-Modified (Lareau, Meek & Roos, 1998). Fatigue was operationalized by the Fatigue component subscale from the Pulmonary Functional Status and Dyspnea Questionnaire-Modified (Lareau, et al., 1998).</p>

Significance

Within chronic disease and self-management science, patient activation has emerged as an integral concept in providing patient-centered, individualized care (Bos-Touwen et al., 2015). This descriptive correlational study expands the limited scientific knowledge of determinants of

patient activation of adults living with COPD in the United States. The identified determinants of patient activation from this study will: (a) inform the nursing care of adults with COPD, (b) expand the knowledge of patient characteristics associated with capacity to engage in necessary self-management behaviors central to COPD care outcomes, and (c) contribute objective targets to apply toward novel intervention design for future COPD self-management research.

The use of theory to guide research has been a long-standing tradition in the advancement of nursing science (Allgood, 2011). Existing conceptual frameworks from nursing, social sciences, or medicine may provide guidance for the exploration and interpretation of emerging health concepts impacting health and wellbeing (Tappen, 2016). In this study, a widely used bio-behavioral model from the social sciences was used to examine a new health outcome concept originally explicated by health economists, with significant relevance to nursing science. Thus, this study demonstrates the importance of sharing among scientific disciplines to expand health knowledge (Waltz, Strickland, & Lenz, 2010). The application of a conceptual model of patient outcomes in chronic disease organized the study of predominant health, individual, and environmental factors, influencing patient activation in this population.

Nurse scientists have been early adopters of patient activation as both a predictor and core outcome measure in chronic disease and self-management research (Hibbard et al., 2015; Moore et al., 2016). Patient activation is a complex, yet modifiable, health behavior that directly reflects self-management efficacy and capacity (Hibbard & Mahoney, 2010). Thus, the determinants that influence patient activation development must be understood just as clearly as the self-management outcomes the concept predicts. Therefore, this study contributes to the National Institute of Nursing Research's strategic research priority to define the mechanisms of

complex health behaviors that underlie self-management efficacy in chronic illness (Grady & Gough, 2014).

The findings from this study have important implications for nursing practice, research, education, and policy. First, for nurses in direct care roles, understanding what patient activation is and how disease and personal factors influence it will have meaningful impact on the assessment, care planning, and educational resources provided to patients and families affected by COPD. Knowledge of the personal and health factors associated with low activation will help nurses to identify those patients at greatest risk for limited self-management capacity and engage them in appropriate care coordination services (Hibbard & Greene, 2013; Naylor, Hirschman, O'Connor, Barg & Pauly, 2013). Second, identification of the determinants of patient activation addresses a gap in knowledge related to patient characteristics necessary for self-management. This research has the potential to advance self-management science research in COPD. Third, understanding the relationships among health outcome factors and patient activation will enhance academic nursing education relative to chronic disease and self-management. Fourth, this study further supports current health policy effort focused on patient engagement in self-care when diagnosed with COPD to decrease the demand for health care resources by this high healthcare utilization group (Evans & Morgan, 2014; Hibbard, Greene, Sacks, Overton & Parrotta, 2016).

Delimitations

The following delimitations provided the boundaries in which this study was conducted.

- The domains of the Revised Wilson Cleary Model (Ferrans et al., 2005) framed the selection of variables to examine as potential determinants of patient activation level in the study population. The domains were validated and specific variable measures

identified from the empirical self-management literature examining people living with COPD, and published examinations of determinants of patient activation.

- Patient activation has been linked to and overlapped conceptually with other behavioral characteristics in the literature, such as self-efficacy, patient empowerment, and patient engagement (Fumagalli, Radaelli, Littieri, Bertele & Masella, 2015). For this study, the conceptual definition and singular tool to assess the concept developed by Hibbard, Stockard et al. (2004) and Hibbard, Mahoney et al. (2005) was used to define the scope of meaning. See Table 1 Definition of Terms in this chapter and Measurement Tools in Chapter III.
- This study includes adults who were diagnosed with COPD, chronic bronchitis, and/or emphysema. Adults with chronic asthma, bronchiectasis, and alpha 1 anti-trypsin deficiency were not included in the sample, as the causes, trajectory, and treatment plans of these obstructive, chronic lung diseases differ from those of chronic bronchitis and emphysema (GOLD, 2018). Chronic bronchitis and emphysema constitute the majority of COPD diagnoses in the United States (CDC, 2017).
- To achieve a sample reflective of people with COPD in the United States, the study sample was drawn from the electronic medical records of a large, national healthcare organization.
- Because of the nature of the survey study design, the ability to write and read the English language was required for participation.
- As most people were at least 40 years of age when breathing symptoms associated with COPD emerged (ALA, 2017), the age of 40 years established the lower threshold for inclusion in the study. No upper limit of age was set for eligibility to participate in the

study. COPD is a chronic, incurable pulmonary condition; thus, people will live with the disease for the remainder of their lives.

- The comprehensive survey tool provided to study participants was comprised of demographic questions and validated, health outcome measures with high reliability in the COPD population. Further detail of the survey tool is provided in Measurement within Chapter III.
- Data was included for analysis from completed survey tools returned from study participants who provided informed consent.
- The Dillman Total Design Method (Dillman, Smyth & Christian, 2014) of survey research provided the procedure for participant recruitment, survey distribution, and data collection. Data collection took eight weeks from the time of initial study mailing to completion of survey collection. The procedure and methodology of this approach is described in Chapter III.

Assumptions

Assumptions from the extant theoretical and research literature underpinned the methods used in this study. First, quality of life and patient activation are complex, multidimensional health constructs that are impacted by health status and unique life circumstances. Second, unobservable health outcome constructs, such as patient activation, functional status, and quality of life, can be objectively measured and understood through use of survey tools and statistical analysis. Finally, study participants were truthful in their self-reported responses to the questions posed in the study survey tool, which comprised the primary data source for this research.

Organization of Remaining Dissertation Chapters

The study is organized into five chapters and associated appendices and references. Chapter I presents an introduction to the research problem, study purpose, research questions guided by a conceptual framework, and the significance of this work to the field of nursing. Chapter II provides a comprehensive review of the theoretical and empirical research literature related to self-management of COPD and patient activation. Chapter III offers a detailed description of the study design and methodology implemented for this study along with a description of the statistical analysis to be conducted. The analysis of the data is detailed in Chapter IV. Finally, Chapter V provides a discussion of the results, conclusions, and recommendations for nursing practice, education, and research.

Summary

Patient activation is an emerging construct predictive of health outcomes in chronic disease (Hibbard & Green, 2014). The personal characteristics and health outcomes that influence the development and maintenance of patient activation in the setting of chronic disease, and specifically COPD, are minimally understood. Adequate patient activation is vital for an individual to self-manage (Hibbard et al., 2015), thus understanding patient activation determinants is imperative for optimal planning and implementation of self-management interventions for people living with chronic disease (Grady & Gough, 2014). Knowledge gained from this quantitative study may expand the limited scientific knowledge of determinants of patient activation in people living with COPD in the United States. Furthermore, this knowledge may directly contribute to clinical care of people with COPD through informed and individualized treatment decision-making by clinicians, nurses, and pulmonary rehabilitation professionals.

CHAPTER II

REVIEW OF LITERATURE

This chapter presents a review of the literature describing the state of the science of self-management in chronic obstructive pulmonary disease (COPD) and patient activation. The review discusses previous research relative to the significance of patient activation on self-management and health outcomes in chronic disease. Additionally, associations among known factors influencing outcomes in COPD and patient activation are identified and organized within the domains of the guiding conceptual model. Lastly, gaps in the empirical and theoretical literature are presented with discussion of how this study was designed to address them.

As introduced in the previous chapter, the objective of this study is to describe and examine the relationships among patient characteristics and health outcome factors, as conceptualized in the Revised Wilson Cleary Model (Ferrans et al., 2005), and to identify the determinants of patient activation among adults living with COPD. The specific aims of this descriptive correlational study are to:

1. Describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of adults with COPD living in the United States.
2. Examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample.

3. Identify the independent predictors of patient activation in the sample.

Search Process

The literature reviewed was identified through several databases, including Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, ProQuest, PubMed, PsycINFO, and Scopus. Key search terms included chronic obstructive pulmonary disease (or chronic lung disease), self-care (or self-management), symptoms, functional status, general perception of health, health-related quality of life, and patient-reported outcomes. The search timeframe was limited to 2006-2016, though earlier landmark works related to self-management were included.

Key terms to identify literature-examining determinants of patient activation included patient activation (or Patient Activation Measure), determinants, correlates, and predictors. The terms were also combined with chronic disease and chronic obstructive pulmonary disease. Papers were included if the mean age of the study sample was 40 years of age or older, congruent with the typical age in which symptoms of COPD were present and diagnoses were made (ALA, 2017), and the identified sample had at least one or more chronic diseases. The literature search was framed between 2004-2018, to include the seminal paper introducing the Patient Activation Measure (PAM) by Hibbard et al. (2004). Patient activation is frequently used interchangeably in the literature with other terms, such as patient engagement and self-management capacity (Fumagalli et al., 2015), so care was taken to include only literature that provided a definition of patient activation consistent with that of Hibbard et al. (2004).

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is a progressive lung disease with no known cure (ALA, 2017). Beyond causing significant debility and requiring frequent health care

utilization (Celli et al., 2015), COPD causes considerable mortality as the third leading cause of preventable death in the United States (ALA, 2017; CDC, 2017). The goals of COPD treatment are to slow lung function decline, limit symptom impact, prevent exacerbations, improve exercise tolerance, maintain function, and improve overall quality of life (Qaseem et al., 2011). Treatment of COPD consists largely of medications and behavior change support (GOLD, 2018). Multiagent medication regimens are prescribed based on the individual's symptom profile, exacerbation history, and severity of airway obstruction (Balkissoon, Lommatzsch, Carolan & Make, 2011; Mannino et al., 2014). Lifestyle and behavior changes target maintaining pulmonary function and limiting disease progression through avoidance of airway irritants (primarily smoking cessation), prompt response to symptom change and physical activity (GOLD, 2018; Rice, Bourbeau, MacDonald & Wilt, 2014). Primary care providers, pulmonologists, and pulmonary rehabilitation providers direct COPD treatment, though nurses provide most of the hands-on education, counseling, and support to patients (Park & Larson, 2016).

State of the Self-Management Science in COPD

Evidence suggests self-management is significantly associated with reduced hospital admissions, improved shortness of breath, and improving quality of life in people living with COPD (Andenaes et al., 2014; Trappenburg et al., 2013; Zwerink et al., 2014). Self-management behaviors associated with optimal health outcomes in COPD include daily monitoring and response to symptoms, smoking cessation, adherence to the medication regimen, engagement in physical activity, monitoring of mood, and maintenance of relationships (Balkissoon, 2016; Effing et al., 2016; Nici et al., 2014; Rice et al., 2014). People with COPD have complex medical and emotional needs, making self-management particularly challenging. Thus, collaboration among all members of the COPD care team, including providers, patients, and their families, is

necessary for successful self-management and achieving shared goals of care (Rice et al., 2014). The “team-based” approach to self-management, known as collaborative self-management (Bourbeau & van der Palen, 2009) is integral to the multicomponent care approach for COPD (Halding & Grov, 2017). Interventions to improve engagement in self-management by those with COPD have been a research priority in the past decade, reflected in the qualitative and quantitative literature (Effing et al., 2016; Jonkman et al., 2016).

Systematic reviews and meta-analyses. Five systematic reviews and meta-analyses were analyzed in this literature review. Most revealed positive effects of collaborative self-management interventions on dyspnea control, decreased healthcare utilization (hospital admissions and total hospital days for respiratory causes), and improved perception of health (Harrison, Janaudis-Ferreira, Brooks, Desveaux & Goldstein, 2015; Jonkman et al., 2016; Kruis et al., 2013). However, authors found it difficult to draw any tangible conclusions for clinical practice from the randomized control trials examined (Harrison et al., 2015; Jonkman et al., 2016; Kruis et al., 2013; Zwerink et al., 2014). The same authors reported high heterogeneity within the self-management interventions delivered and among the outcome measures. These factors and inadequate statistical power prevented pooling of data for analysis to determine the most effective approaches for collaborative self-management of COPD (Harrison et al., 2015; Jonkman et al., 2016; Kruis et al., 2013; Zwerink et al., 2014). Furthermore, the authors concluded that insufficient evidence existed to explain the characteristics of responders from non-responders across studies reviewed (Zwerink et al., 2014; Kruis et al., 2013). Authors called for greater description of the characteristics of study participants to identify factors associated with likelihood of response to treatment (Harrison et al., 2015; Jonkman et al., 2016; Kruis et al., 2013).

Randomized control intervention trials. Numerous randomized control trials of collaborative self-management interventions have been conducted. Unfortunately, health outcome results have been highly variable (Benzo et al., 2012; Bucknall et al., 2012; Rice et al., 2010; Titova et al., 2017), including adverse events (Fan et al., 2012). As discussed in the published meta-analyses and systematic reviews, randomized control trials have been inconclusive in identifying and validating effective means to affect self-management behaviors necessary to improve COPD health outcomes (Bucknall et al., 2012; Fan et al., 2012). However, some were successful in improving health outcomes that matter most to patients, namely dyspnea control, mastery of the disease, and quality of life (Benzo et al., 2012, Rice et al., 2010). Unfortunately, these studies were viewed as negative because they did not achieve their primary aims of improved exercise capacity or decreased all-cause mortality. While no single cause of negative results or adverse events were identified, authors of some of the studies posited that some participants with COPD might simply not have been *capable* to self-manage (Bucknall et al., 2012; Fan et al., 2012). The mixed results of these studies may suggest that the heterogeneous, complex nature of COPD might undermine any intervention that is not effectively tailored to the capabilities of the individual.

Self-management engagement. Several qualitative studies have examined the factors people with COPD attribute to their engagement in self-management behaviors (Benzo, Wetzstein, Neuenfeldt & McEvoy, 2015; Chen, Chen, Lee, Cho & Weng, 2008; Disler et al., 2012; Sohanpal, Seale & Taylor, 2012). Less than one-half of people with COPD engage in the recommended self-management practices (Bender, 2014; Nici et al., 2014). Those who do self-manage prioritize what they do based upon the most significant burdens the disease places on them at any given time (Bender, 2014; Bischoff et al., 2012; Bucknall et al., 2012).

Chen et al. (2008) conducted a qualitative study to describe the self-management behaviors people with COPD found most important to integrate into their daily lives. In their sample the self-management behaviors that carried the most meaning were symptom management (primarily dyspnea and fatigue), being physically active to support regular daily activities, making healthy lifestyle choices (e.g., smoking cessation, good nutrition), keeping emotions in check, and controlling their environment (avoiding cold). Sohanpal et al. (2012) sought to understand the reasons people with COPD either regularly attended or skipped collaborative self-management programs. They found that people who were more motivated and had prior COPD knowledge were most engaged in attending group-based, peer led programs. Participants acknowledged that programs tailored to their strengths and supported their capabilities kept them wanting to come back and be engaged (Sohanpal et al., 2012). This view from the participants is not surprising, as individualized strengths-based approaches to self-management optimize an individual's patient activation level for self-care (Hibbard & Greene, 2014). When people are offered self-management education and support matched to their current capabilities they are more likely to be adherent to recommended self-management behaviors (Jonkman et al., 2016).

Sohanpal et al. (2012) found feeling too ill was the primary deterrent for patients to attend self-management programs following hospitalization for COPD exacerbations. Alternatively, people who felt too well following hospital discharge indicated their quick recovery as a motivational barrier to attendance. Other barriers included logistical factors (distance and travel challenges), physical limitations (weakness and portable oxygen burden), and emotional struggles (Sohanpal et al., 2012). In 2015 Benzo et al. found similar barriers to participation in post-COPD exacerbation self-management programming. Thematic coding

revealed prevailing factors patients provided for not wanting to attend a pulmonary rehabilitation program, such as lack of interest, feeling too ill or frail, being “too busy” to attend, travel difficulties, and lack of social support (Benzo et al., 2015). These qualitative studies illuminated the diverse challenges to self-management engagement perceived by people living with the disease. The breadth of barriers is congruent with the multifactorial, holistic impact of COPD (Jerant, van Friederichs-Fitzwater & Moore, 2005). Unfortunately, this heterogeneity prevents identification of tangible intervention targets to circumvent lack of self-management engagement by people with COPD (Kaptein et al., 2014). However, the results of these studies speak to the need of examining factors that contribute to engagement and activation to self-manage in a conceptually organized manner to achieve understanding of the findings for practice and research advancement.

Self-management in COPD. Over the past two decades systematic reviews and meta-analyses provided a lens to view the large literature base of self-management science in COPD. Self-management is integral to the treatment of COPD and successful engagement is associated with better function and quality of life of those with the disease. The high heterogeneity found in COPD self-management trial intervention designs, outcomes measured, and study results undermine the ability to draw conclusions and establish an evidence base for practice (GOLD, 2018; Nici et al., 2014; Rice et al., 2014). However, it is important to acknowledge that the self-management interventions studied were necessarily multicomponent to address the multidimensional approach required to treat COPD. Moreover, the heterogeneity of outcomes chosen to measure intervention effectiveness is a common problem in self-management science (Grady & Daley, 2014), not just in COPD research.

The state of the science reflects poor understanding of the unique patient characteristics associated with self-management success and risk for failure (Nici et al., 2014; Titova et al., 2017). What is known from review of the literature is passive education to acquire disease knowledge and action plans for self-treatment of exacerbations are not sufficient to support COPD patients to self-manage (Bodenheimer, Lorig, Holman & Grumbach, 2002; Jonkman et al., 2016; Kaptein et al., 2014; Trappenburg et al., 2013). Collaborative self-management plans must be designed to engage people at a level appropriate to their functional, psychosocial, and cognitive/behavioral capability (Grady & Gough, 2014). Active, individualized interventions that include bio-physiological management and the role of cognition and emotions are needed (Kaptein et al., 2014). Some authors concluded that cognitive-behavioral influences might be at the heart of self-management capacity for those with COPD (Kaptein et al., 2014; Korpershoek et al., 2016). Thus, studies that examine behavioral constructs associated with self-management capacity, such as engagement, motivation, and patient activation, are needed to advance patient-centered COPD self-management interventions (Korpershoek et al., 2016). Recently, patient activation was included as an outcome measure in a COPD self-management intervention trial (Titova et al., 2017). Adoption of patient activation as a core outcome measure in this population has yet to be reported in the COPD literature.

Patient Activation

Patient activation emerged as a conceptual focus of health care consumerism and engagement research to examine factors influencing self-management outcomes in the growing population of people with chronic diseases (Hibbard et al., 2016). In 2004 Hibbard, Stockard, Mahoney, and Tusler examined the concept of patient activation using the Delphi technique to establish an operational definition and create a psychometrically sound measure patient

activation for use in clinical and research settings. The authors credit theoretical influences from Bandura's (1991) social cognitive theory, Di Clemente et al.'s (1991) Transtheoretical Model of Change, and Wallston, Stein and Smith's (1994) health locus of control as shaping the item pool used in their Delphi approach. They conceptualized and operationalized an individual's *capacity* to engage in self-care behaviors in chronic disease as *patient activation*. Patient activation is defined as a measure of self-management capacity, reflecting the skills, knowledge, and confidence to actively engage as a self-manager (Hibbard et al., 2004).

Though Hibbard's (2004) work is considered seminal in introducing the concept of patient activation in the chronic disease literature, the term first appeared in 1982. Morisky, Bowler, and Finlay (1982) described increased *patient activation*, subsumed as being comprised of locus of control, knowledge, and compliance, as the outcome of a cognitive-behavioral intervention to increase patient engagement in hypertension self-management activities. Though pre-dating Hibbard et al. (2004), Morisky et al.'s (1982) description of *patient activation* quite similarly includes *knowledge, skills*—demonstrated by compliance to carry out actions to manage and *confidence* to take control over their disease management. Interestingly, Hibbard et al., (2004) did not include Morisky et al.'s (1982) work as a reference in their paper. The term appears again in 1998 in Wagner's Chronic Care Model (Wagner, 1998). Here, the informed *activated patient* is an integral element of the coordinated process of delivering chronic disease care to achieve optimal health outcomes (Wagner, 1998).

Since the inception of the first 22-item Patient Activation Measure in 2004, more than 200 peer-reviewed research papers have been published examining patient activation as: (a) a valid assessment tool for self-management capacity; (b) a framework for designing and implementing behavioral change interventions for adoption of self-management behaviors; and,

(c) a valid and reliable outcome measure and predictor of health outcomes across multiple chronic conditions, age, and sociodemographic groups (Hibbard et al., 2015; Moore et al., 2016; Skolasky et al., 2011). The growing evidence base suggests that people with higher patient activation levels have better health outcomes in the context of chronic illness; however, the factors that determine or mediate patient activation within individuals are still relatively unknown (Hibbard et al 2015; Schmaderer, Zimmerman, Hertzog, Pozehl & Paulman, 2016).

Patient activation and self-management. Several relationships exist among self-management behaviors by people with chronic disease and patient activation. Symptom monitoring and medication adherence were associated with higher patient activation (Dixon et al., 2009; Graffigna et al., 2017; Hibbard & Tusler, 2007). Maintaining a healthy weight, following exercise regimens, and attending healthcare appointments were also associated with higher patient activation (Bolen et al, 2014; Hibbard et al., 2007; Wong, Peterson, & Black, 2011).

Four studies discussed self-management activities related to chronic lung diseases and patient activation. Hibbard and Tusler (2007) explored adult asthma, self-management behaviors, and relationships among these with patient activation. They found that knowledge of how to respond to an asthma attack and use of stress management skills in the setting of symptom change were significantly related to higher patient activation levels in their sample. Two studies in this review found the degree of medication adherence to control shortness of breath and wheezing was directly related to patient activation levels (Mosen et al., 2007; Skolasky et al., 2010). Among a cohort of working adults with COPD, Fowles et al. (2009) identified a strong association between patient activation level and reported self-management activities focused on maintaining physical and role functions.

Intervention studies have emerged examining the effects self-management support programs tailored to the level of patient activation on chronic disease health outcomes. Self-management studies utilizing patient activation-tailored interventions in heart failure, diabetes, and multimorbidity found statistically significant improvements in patient activation level, engagement in self-management behaviors, and health outcomes (Bolen et al., 2014; Deen, Lu, Rothstein, Santana & Gold, 2010; Hibbard et al., 2007; Hibbard, Greene & Tusler, 2009; Ryvicker, Feldman, Chiu & Gerber, 2013; Shively et al., 2013; Van Do, Young, Barnason & Tran, 2015). The utility of patient activation in these studies was demonstrated two-fold. First, interventions were tailored to the current patient activation level of the participants. A step-wise approach to delivering the intervention aimed to build confidence in patients to self-manage was consistent with the theoretical influences underpinning the conceptual definition of patient activation (Shively et al., 2013). Second, the sensitivity of the PAM allowed for determining correlations among patient activation change and health outcome change in the samples studied. Most patient activation-tailored intervention studies showed positive relationships among self-management interventions and improved outcomes—health and patient activation level (Deen et al., 2010; Hibbard et al., 2009; Shively et al., 2013), but others showed no change in patient outcomes (Bolen et al., 2014; Ryvicker et al., 2013; Titova et al., 2017).

The mixed findings of patient activation-tailored self-management trials are congruent with the crux seen in the COPD self-management intervention literature. It is unclear why some patient activation-tailored self-management interventions were not effective in changing behavior. Knowledge that patient activation level is modifiable (Hibbard & Greene, 2013) and responsive to strengths-based approaches to self-management support (Hibbard & Mahoney, 2010), suggests that complex and multidimensional factors are at play in the development of

patient activation within people who have chronic disease. Interest in understanding the complexity underpinning patient activation development in individuals has led to several studies examining the determinants of patient activation level in people with chronic diseases.

Determinants of Patient Activation in Chronic Disease

Examining the impact of demographic, psychosocial, and disease-specific factors influencing the development of patient activation among people with chronic disease has become a recent focus of nursing inquiry. Several studies have examined a variety of patient-centered factors as correlating to or predictors of patient activation level (Bos-Touwen et al., 2015; Chen, Chen, Lee, Cho & Weng, 2014; Chubak et al., 2012; Goodworth et al., 2014; Korpershoek et al., 2016; Mazanec, Sattar, Delaney & Daly, 2016; Schmaderer et al., 2016). Secondary goals of these studies were to understand the potential risk factors for limited self-management capacity and, thus, illuminate modifiable targets for individualized approaches to self-management interventions.

Some studies identified a theoretical framework as underpinning variable choice, study design, or framing the results (Chen et al., 2014; Chubak et al., 2012; Goodworth et al., 2014). The Andersen Behavioral Model (Chen et al., 2014) and Chronic Care Model (Chubak et al., 2012) have healthcare delivery systems and environments at their core. Thus, the studies were limited to examining environmental factors influencing patient activation level, not including the impact of chronic disease on individuals. Similarly, the internal, cognitive processes of Self-Efficacy Theory limited the study of determinants by Goodworth et al. (2012) to inclusion of individual characteristics and disease-specific health outcomes. Other studies examined variables found to be relevant to health outcomes in the disease-specific literature of their populations of interest in lieu of using a guiding model or framework (Bos-Touwen et al., 2015; Korpershoek et

al., 2016; Mazanec et al., 2016; Schmaderer et al., 2016). Both approaches to the study of determinants of patient activation yielded a diverse array of variables for examination.

Disease-specific determinants. Determinants of patient activation within specific chronic diseases have been studied. Chen and colleagues (2014) examined a national sample of people with depression to identify contextual factors associated with mental healthcare utilization. These factors formed the basis of a framework for explaining determinants of patient activation level in this population. Through multivariate regression, characteristics of the environment in which people lived and site of usual health care (local primary care clinic) were significant in predicting higher levels of patient activation, explaining 15% of the variance in patient activation scores. Goodworth et al. (2014) based their cross-sectional study of persons with multiple sclerosis on Bandura's self-efficacy theory, noting Hibbard and Mahoney's (2010) assertion that efficacy is necessary to establish one's concept as a self-manager in chronic disease. They examined mood, self-efficacy in multiple sclerosis, quality of life, and sociodemographic factors through hierarchical regression modeling. Self-efficacy and educational level were positively related to patient activation level, while depression was negatively related to patient activation level. These variables explained 35% of the variance in patient activation level in their sample. O'Malley and colleagues (2017) examined patient characteristics and clinical factors as determinants of patient activation among prostate and breast cancer survivors. Results from their cross-sectional survey indicated race, marital and employment status, income, and ease of access to their healthcare providers were significantly positively associated with patient activation level among prostate cancer survivors, but only provider access and time spent with them were positive predictors among breast cancer survivors. Associations among patient characteristics and patient activation were identified by

analysis of variance, however, the assertions of these factors as predictors of patient activation are unsubstantiated by the lack of linear regression used in the statistical analysis.

In these studies the variables examined and shown to predict patient activation among community-dwelling adults are congruent with Ferrans et al.'s (2005) definitions of characteristics of the individual and the environment and their assertion that these characteristics can directly influence health outcomes in chronic disease. Thus, these disease-specific studies suggest that characteristics of the individual (Goodworth et al., 2014; O'Malley et al., 2017) and their environment (Chen et. al., 2014; O'Malley et al., 2017) are important factors to consider in examining determinants of patient activation among people with COPD.

Disease transcending determinants. Other studies used cross-sectional design to investigate disease-transcending determinants of patient activation across multiple chronic conditions (Bos-Touwen et al., 2015; Schmaderer et al., 2016). Bos-Touwen et al. (2015) examined 19 clinical, demographic, and psychosocial determinants of activation in a cross-sectional survey study of patients with chronic renal, heart, pulmonary, or endocrine diseases. Through multivariate regression analyses, the authors found that disease severity, health-illness perceptions, mood, social support, sociodemographic factors, and co-morbidity impact explained 16% of the variance in activation levels across chronic disease sub-groups (Bos-Touwen et al., 2015). Schmaderer et al. (2016) explored demographic, psychosocial, and clinical factors as determinants of patient activation level among people with multimorbidity. The authors included commonly used patient-reported outcomes tools (i.e., PACIC, PROMIS-29, EuroQOL 5) to survey patients just prior to discharge for hospitalizations resulting from exacerbation of one of more chronic conditions. Multivariate regression yielded three factors explaining 26% of the variance in patient activation scores in the sample. These factors were health literacy, satisfaction

with one's social role, and level of involvement in chronic illness care team (Schmaderer et al., 2016). These two studies examined highly heterogeneous factors across multiple disease states as possible determinants influencing patient activation in chronic disease. The independent variables examined in these studies aligned with each of the domains described in the Revised Wilson Cleary Model (Ferrans et al., 2005), adapted to guide this study. Interestingly, the predictors identified were reflected in each of the domains of the Revised Wilson Cleary Model (Ferrans et al., 2005), except symptoms and overall quality of life. The results offer that complex and highly integrated factors influence patient activation level among people living with multimorbidity. The disease-transcending determinants of patient activation were relevant to the design of this study, as most people with COPD have at least two other co-morbid chronic conditions (Benzo et al., 2010; Celli et al., 2015).

Longitudinal studies of determinants. Building on the frequently used, cross-sectional approach, longitudinal studies were conducted to examine disease-transcending determinants of patient activation. Chubak et al., (2012) followed older adults with diabetes and heart disease over one year as part of an integrated health delivery system. Self-rated health, serious adverse events from chronic disease (e.g., ED visits, hospitalizations), satisfaction with chronic disease care, patient activation, and measures of disease impact was collected via a survey during Medicare enrollment visits. Though many of the variables were correlated, only older age and worse self-rated health (i.e., Fair or Poor) were independent predictors of decreased patient activation level from baseline to one year (Chubak et al., 2012). Hibbard et al. (2015) published a report examining patient activation level as a predictor of health outcomes over time. Participants were reexamined four years after first response to a national panel survey of people with diverse chronic conditions, and the authors found that consistent self-management practices, increased

function, and decreased costly health care use were enduring outcomes of high patient activation at baseline (Hibbard et al., 2015). When patient activation changed over the four-year period, it did so with health outcomes moving in the same direction (e.g., activation increased, positive outcomes occurred; activation decreased, negative outcomes occurred). Congruent with Chubak et al.'s (2012) findings, older age and poorer general perception of health were strongly associated with lower patient activation scores (Hibbard et al., 2015). Recently, Mazanec and colleagues (2016) studied relationships among symptoms, mood, physical and role function, and patient activation before and four months after surgery among colorectal cancer survivors. Interestingly, they found patient activation to be high (Level 3) and stable across time in this population. In linear mixed effects models, negative emotions were significantly associated with low patient activation (Levels 1 and 2) across all time points. Their finding is congruent with Hibbard and Mahoney's (2010) cross-sectional study that indicated patient activation is strongly linked to the experience of positive and negative emotion in daily life. All the identified predictors of patient activation that endure over time among people with chronic conditions align with domains of the Revised Wilson Cleary Model (Ferrans et al., 2005), further supporting the use of the model in the current study.

State of the Science for Determinants of Patient Activation

The growing body of literature described several determinants of patient activation in the setting of community dwelling adults with one or more chronic diseases. Of these, demographic and socioeconomic characteristics, mood, role status, social support, perceived health status, and the impact of one or more chronic disease were shown in one or more studies to predict patient activation level. This evidence provided further support for using the Revised Wilson Cleary Model to study determinants of patient activation among adults with COPD in

this dissertation research. Though correlations could not be drawn across the studies, as each examined different variables of interest, age, general perception of health, negative mood states, and socioeconomic status appeared most frequent as determinants in multiple studies. Therefore, inclusion of these factors was imperative in the study of patient activation predictors in the setting of COPD.

Patient Activation and COPD

Little is known about how the complex, systemic nature of COPD affects patient activation (Evans & Morgan, 2014; Korpershoek, 2015). Although patient activation can be objectively measured with the PAM (2004), it is not typically assessed in COPD clinical visits (Korpershoek et al., 2016). Evidence of patient activation as a predictor of chronic disease outcomes is particularly relevant in the domain of COPD care. COPD is a resource-intensive disease process, imparting high self-care burden on patients and costly health care utilization (Celli et al., 2015). Health care utilization rates, including 30-day hospital readmission, and health care costs of people with COPD are approximately twice that of healthy age and sex-matched controls (Green et al., 2015; Mitchell et al., 2014; Roberts et al., 2000). Self-management has been associated with decreased incidence of hospitalization for acute exacerbation of COPD (Zwerink et al., 2014), which is the leading driver of COPD-related costs worldwide (Dhamane et al., 2015). Adults with higher activation were more likely to participate in recommended activities associated with collaborative self-management treatment plans for COPD (Dixon, Hibbard & Tusler, 2009). Charlot and colleagues (2017) found patient activation mediated the effect of self-management education on hospitalization rates among urban, Caucasian adults. One standard deviation increase in PAM score was associated with 18% reduced odds of being hospitalized with a COPD-related diagnosis, supporting patient activation

as a modifiable target to address readmission rates in this population (Charlot et al., 2017). Examining how patient activation is influenced in this population is warranted.

Determinants of patient activation in COPD. To date, only one Dutch study explored determinants of self-management capacity, operationally defined as patient activation, among people living with COPD. The work by Korpershoek et al. (2016) utilized a cross-sectional survey design with electronic medical data abstraction to identify COPD-specific determinants of self-management capacity. The sample ($N = 296$) included adults with COPD living in the community and in skilled nursing facilities. Fifteen independent variables were chosen from the extant COPD literature (Korpershoek et al., 2016), which reflected a diverse examination of biological, behavioral, and psychosocial factors influencing self-management capacity. Multivariate logistical regression analyses revealed six determinants explaining 17% of the variance in self-management capacity; these included anxiety, illness perception, Body Mass Index, COPD severity, comorbidities, and age (Korpershoek et al., 2016). It is important to note that Korpershoek's study cohort was included in the previously described multi-chronic disease study of Bos-Touwen et al. (2015).

Korpershoek et al.'s (2016) work provides seminal insight to the individual patient characteristics associated with patient activation among people with COPD. Several of these predictors were included in the current study. Though Korpershoek et al.'s (2016) sample was large, inclusion of participants living in skilled care environments who were not independently responsible for managing their treatment plan raised questions to the meaning of the results. Self-management of chronic disease is a phenomenon of community dwelling persons, not typically associated with skilled care settings (Bodenheimer et al., 2002; Lorig & Holman, 2003).

Therefore, this study of determinants of self-management capacity focused on people with COPD who were independent in their health management.

Outcomes of COPD and Patient Activation Via the Revised Wilson Cleary Model

Patient activation is a multidimensional, patient-reported health outcome in chronic disease. Though theoretically influenced by several behavioral frameworks (Hibbard et al., 2004), a conceptual or theoretical framework describing the process of patient activation in individuals and populations with chronic disease has yet to be reported in the literature. Thus, adaptation of existing theoretical and conceptual frames would be needed to examine the concept in the context of specific diseases. The Revised Wilson Cleary Model (Ferrans et al., 2005) is a descriptive, explanatory framework that categorizes personal and health phenomena and proposes relationships between and among these phenomena (Tappen, 2016). The model and the original work by Wilson and Cleary (1995) were described in detail in Chapter I. The existing evidence of relationships among health outcomes, characteristics of people with COPD, and shared associations with patient activation, will be organized within the domains of the Revised Wilson Cleary Model (Ferrans et al., 2005). Further, evidence of the application and adaption of the conceptual framework in similar empirical research is presented.

Characteristics of the Individual

Characteristics of the individual are the demographic, developmental, psychological, and biological factors that influence health outcomes in chronic disease (Ferrans et al., 2005). These characteristics impact all antecedents of quality of life in the Revised Wilson Cleary Model (Ferrans et al., 2005), and may moderate relationships among the health outcomes as well. In this study, specific demographic, psychological, and biological factors were selected as important characteristics of the individual with COPD, which could impact patient activation level.

Demographic factors. Age is negatively associated with COPD health outcomes (Croft, et al., 2018) and patient activation level (Dunlay, Griffin, Redfield & Roger, 2017; Hibbard et al., 2015; Korpershoek et al., 2016). Evidence offers several gender differences in expression of symptoms, disease progression, and exacerbation trajectories, favoring greater morbidity and mortality for women with COPD (Balkissoon, 2011; Pruitt, 2014; Jenkins et al., 2017). Inconsistent relationships between gender and patient activation level have been identified. Several studies suggested women are more activated than men (Fowles et al., 2009; Hibbard, Mahoney et al., 2005; Hibbard, Greene et al., 2015; Young et al., 2017), although Lubetkin, Lu, and Gold (2010) found the opposite to be true. Authors recommended the role of gender and patient activation should be considered cautiously, as many published patient activation studies had disproportionately large numbers of women in their samples (Fowles et al., 2009; Goodworth et al., 2016; Hibbard et al., 2005, 2007, 2015, 2016).

Race and ethnicity associations with health outcomes in COPD are thought to be largely a component of socioeconomic status (GOLD, 2018; Mannino et al., 2014), as COPD is most prevalent among white, non-Hispanics in America (Croft et al., 2018; Tilert et al., 2013). Low socioeconomic status has been associated with limited functional status and poorer lung function, thus, imposing risk for increased COPD severity and acute exacerbations (Dhamane et al., 2015; Eisner et al., 2011). Racial and ethnic minorities have demonstrated lower levels of patient activation than their Caucasian counterparts (Alexander, Hearld, Mittler & Harvey, 2012; Hibbard et al., 2007; Hibbard & Cunningham, 2008; Lubetkin et al., 2010). Like the health outcomes in COPD, more recent literature argued that socioeconomic status better explains the variance in patient activation level among these groups (Hibbard et al., 2015; O'Malley et al., 2018).

Educational level (GOLD, 2018; Eisner et al., 2011), increased health literacy, (Ryvicker et al., 2013; Smith, Curtis, Wardle, von Wagner & Wolf, 2013), and greater self-management engagement (Lorig & Holman, 2003; Trappenburg et al., 2013) were positively correlated with better health outcomes in COPD and patient activation levels (Bos-Touwen et al., 2015; Fowles et al., 2009; Hibbard et al., 2007, 2015; Marshall et al., 2013). Limited education attainment and income were independently related to greater risk of acute COPD exacerbation when controlling for race and ethnicity (Eisner et al., 2011).

Employment has also been positively correlated with patient activation levels, self-management engagement, and positive health outcomes in COPD (Eisner et al., 2011; Fowles et al., 2009; Grodner et al., 1996; Smith et al., 2000). Among older adults with COPD, participating in paid work was associated with greater perception of physical health and quality of life (Andenæs, Bentsen, Hvinden, Fagermoen & Lerdal, 2014). Earned income, a measure of socioeconomic status resulting from employment, has been correlated with engagement in health care activities (e.g. seeing a health care provider, following treatment plans, compliance with medication regimens) and self-reported health among adults with COPD (Eisner et al., 2011; Fowles et al., 2009; Steer, Gibson, & Bourke, 2010).

Psychological factors. Positive and negative affect are inextricably linked to comorbid mood disorders and health outcomes in COPD and patient activation. Anxiety, a negative affect state (Cohen & Pressman, 2006), can be both comorbidity and symptom of COPD (Yohannes & Alexopoulos, 2014), directly influencing the symptom of dyspnea (Carrieri-Kohlman et al., 2010). Clinical depression and depressive symptoms are also associated with negative affect or mood (Cohen & Pressman, 2006). Comorbid depression and anxiety often appear together in people with COPD, with prevalence rates as high as 42% (Yohannes & Alexopoulos, 2014).

Negative affective arousal induces sympathetic responses of increased breathing and heart rate, exacerbating the sensation of dyspnea and feelings of fear in people with COPD (Cohen & Rodriguez, 1995). In turn, strong negative emotional responses to dyspnea provoke increased attention to breathing, inducing further anxiety, and yielding avoidance behaviors. The resulting vicious negative cycle erodes functional performance (DiNicola, Julian, Gregorich, Blanc & Katz, 2013; Nguyen, Donesky-Cuenca & Carrieri-Kohlman, 2008) and quality of life among people with COPD (Carrieri-Kohlman et al., 2010; Norweg & Collins, 2013). Benzo, Abascal-Bolado and Dulohery (2016) found positive affect, manifested as feelings of optimism and happiness, to be independently associated with quality of life and mediated the relationship between self-management ability and quality of life among adults with COPD.

Positive affect has been associated with higher patient activation levels and engagement in self-management behaviors by people with chronic disease (Charlson et al., 2014; Hibbard & Mahoney, 2010; Graffigna et al., 2017). Several studies have shown that negative affect states, such as anxiety and depression, are prevalent among people reporting lower activation scores (Gerber et al., 2011; Hibbard & Cunningham, 2008; Hibbard & Mahoney, 2010; Smith et al., 2013). Further, researchers have found that people with negative affect and concomitant low patient activation scores were more likely to have been hospitalized or visited an emergency department, than those with positive affect states (Greene & Hibbard, 2012; Hibbard et al., 2015).

Biological factors. Increased Body Mass Index is a biological factor associated with negative health outcomes (Eisner et al., 2011; Steer et al., 2010) and decreased patient activation levels of people with COPD (Korpershoek et al., 2016; Liu et al., 2014). The length of time people live with a COPD diagnosis is positively correlated with negative health outcomes (Steer

et al., 2010) and increased COPD-related morbidity (GOLD, 2018). Similarly, the length of time with chronic disease is associated with fluctuations in patient activation level (Chubak et al., 2012; Hibbard et al., 2015; Skolasky et al., 2011). The longer people live with COPD, the greater the incidence of exacerbations, diminished function, and reports of negative quality of life (Andenæs et al., 2014; Balkissoon, 2016; Benzo et al., 2010). Disease burden and exposure to care providers, rehabilitation services, and disease-specific education, over time are factors that may influence patient activation level of people living with COPD (Hibbard et al., 2007).

Characteristics of the Environment

Characteristics of the environment are the social interactions and physical surroundings, which influence the individual's perception of quality of life in the context of chronic disease (Ferrans et al., 2005). Friends, family, and caregivers represent the interpersonal and social influences of health within one's environment. The physical setting in which one lives, works, and engages socially influences health outcomes (Ferrans et al., 2005). Previous studies in COPD self-management and patient activation proposed that where people live (rural or urban) and whom they live with (alone or with significant others) are relevant characteristics of the environment influencing health outcomes.

Limited access to care providers and COPD resources (i.e., pulmonary rehabilitation or Better Breathers Groups) in rural areas have been implicated as causal factors for increased risk of COPD exacerbations and exacerbation-related mortality (Croft et al., 2018; NQMC, 2017). Older adults living in rural settings report low patient activation scores (Young et al., 2017). Relationships with physicians (Alexander et al., 2012; Wong et al., 2011), satisfaction with overall chronic disease care (Boyd et al., 2014), and increased access to primary care within the immediate community (Chen et al., 2014; Lubetkin et al., 2010) are associated with greater

patient activation levels. These factors were also associated with improved self-management among people living with COPD and heart failure (Dunlay et al., 2017; Van Do et al., 2015). Increased patient activation levels and improved health outcomes among older people living in urban, metropolitan settings were attributed to greater access to health care and less social isolation (Chen et al., 2014). Others found conflicting results, despite increased concentration of resources; older chronically ill adults living in inner-city settings also reported lower patient activation levels (Maranda, Deen, Elshafey, Herrera & Gold, 2014). In contrast, other authors described limited health care access and isolation as contributing to lower patient activation scores among older adults living in rural settings (Young et al., 2017).

Marital status and living arrangements are relevant to the social support and health outcomes of people with COPD and have been associated with patient activation levels. Social support is positively correlated with maintaining daily physical activity following pulmonary rehabilitation programming and decreased morbidity and mortality following hospitalization for exacerbation among adults with COPD (Meshe, Claydon, Bungay & Andrew, 2017). Social support has been positively correlated with patient activation and engagement in self-management activities across chronically ill populations (Bos-Touwen et al., 2015; Fowles et al., 2009; Hibbard & Cunningham, 2008; Hibbard et al., 2007). Living alone has been associated with lower patient activation levels (Fowles et al., 2009; Korpershoek et al., 2016), frequent health care utilization (Roberts et al., 2016), and increased risk of exacerbation requiring hospitalization among people with COPD (Dhamane et al., 2015).

Biological Function

Biological function broadly reflects the dynamic processes that support life (Wilson & Cleary, 1995). This domain includes the genetic, cellular, and whole organ system processes that

are impacted by disease (Ferrans et al., 2005). Ferrans et al. (2005) assert that progressive biological dysfunction can directly or indirectly affect all other domains of health, thus optimizing biological function is integral to achieving a state of health within illness. COPD is a multifaceted lung disease characterized by progressive obstruction within the airways and damage to the lung parenchyma (Balkissoon et al., 2011). Spirometric measures of lung function reflected the objective measure of biological function in this study.

Lung function and disease severity. Spirometry is a breathing test that evaluates ease and volume of airflow through the lungs and airways. FEV₁ less than 80% of predicted volume of airflow, based on gender, race, height, weight, and age, is a diagnostic criterion of COPD (Celli et al., 2015; GOLD, 2018). COPD severity is classified by FEV₁ values in the Global Strategy for the Diagnosis, Management, and Prevention of COPD (GOLD, 2018). GOLD (2018) classifies COPD by four stages of severity: (a) COPD stage 1: mild (FEV₁ <80% predicted), (b) COPD stage 2: moderate (FEV₁ 50-80% predicted), (c) COPD stage 3: severe (FEV₁ 30-50% predicted) and (d) COPD stage 4: very severe (FEV₁ <30% predicted). Spirometry was chosen as the biological variable of interest in this study as measures of airway obstruction are: (a) a diagnostic and staging requirement for COPD, (b) central to treatment recommendations, and (c) integral to characterizing the sample in the COPD literature.

Celli et al. (2015) have stated that biological function, assessed by FEV₁, does not fully explain the impact of COPD on health outcomes (Celli et al., 2015). Airflow obstruction has been poorly correlated with dyspnea, exercise tolerance, and health-related quality of life across several studies (Benzo et al., 2010; Bucknall et al., 2012; Guyatt et al., 2007). However, Tsukino and colleagues (1996) found FEV₁ independently predicted health-related quality of life of

people living with COPD. Severity of COPD, categorized by FEV₁, was found to be a predictor of patient activation level in people with COPD by Korpershoek et al. (2016).

Symptoms

Symptoms reflect a person's perception of an abnormal physical, emotional, or cognitive state (Ferrans et al., 2005; Wilson & Cleary, 1995). Symptom assessment and management are crucial activities in self-management of COPD, shifting the focus of care from "cellular and organism level to a (whole) person level." (Ferrans et al, 2005, p. 339). Dyspnea and fatigue are the two most common and progressive symptoms experienced by people with COPD (Peters et al., 2010; Tel et al., 2012). Minimizing symptom burden is essential to maintaining quality of life, thus a priority in COPD treatment plans (van der Molen, Miravittles & Kocks, 2013).

Biomedical treatments are focused on controlling dyspnea caused by airway inflammation and reactivity through use of pharmaceuticals, prevention of opportunistic infections, and strengthening the respiratory and large muscle groups (Qaseem et al., 2011). Research proposed the physiological mechanisms impacting the perception of dyspnea and fatigue by people with COPD contribute to declining function and quality of life (Paes et al., 2015). Fatigue is prevalent among people living with COPD; nevertheless, the mechanism of fatigue is poorly understood (Walke et al., 2007). Fatigue is strongly associated with dyspnea (Kapella et al., 2006) and low self-rated health (Nguyen et al., 2008) in this population.

Symptoms in COPD have been associated with negative outcomes across multiple domains of the Revised Wilson Cleary Model (Ferrans et al., 2005). Liu et al. (2014) found older adults with COPD were more likely to have difficulty with at least one instrumental activity of daily living and less likely to engage in social activities due to dyspnea and fatigue, as compared a healthy national sample. Further, symptoms contribute to poor general perception of health in

COPD. Bentsen, Henriksen, Wentzel-Larsen, Hanestad, and Wahl (2008) found mood symptoms, such as depression and anxiety, and dyspnea explained 35%-51% of the variance in self-rated health among people with COPD, as compared to the general population. More recently, Marvel and colleagues (2016) reported that symptoms significantly contributed to lower self-rated health and satisfaction with role function, even when patients received the standard of care for COPD, which included collaborative self-management support.

Symptom monitoring and activities to control or alleviate symptom burden are basic elements of self-management in chronic disease. However, symptoms and their relationship with patient activation have been minimally described in the literature. Kukla, Salyers and Lysaker (2013) examined the relationship between patient activation and symptoms among adults with schizophrenia. They found that people who experienced emotional discomfort symptoms (e.g., hopelessness, depression) attributed to living with chronic mental illness, reported lower patient activation scores than counterparts with physical chronic diseases and associated physical symptoms (Kukla et al. 2013). Dyspnea, fatigue, and pain symptoms were also found to be related to, but not predictive of activation level, in studies of patient activation determinants (Bos-Touwen et al., 2015; Korpershoek et al., 2016; Schmaderer et al., 2016).

Functional Status

Functional status represents a person's ability to *perform* tasks in multiple domains reflecting adequate physical, social, role, and emotional *capacity* (Ferrans et al., 2005). Functional capacity describes one's *capability* to perform specific physical, social, emotional, or cognitive tasks, whereas functional performance reflects the *actions* performed in daily life (Wall, 2007). The physical and role domains of functional status, as defined by Ferrans et al. (2005), are most relevant in self-management of COPD (Reardon, Lareau & ZuWallack, 2006).

The negative effects of COPD reach far beyond the respiratory tract, thus posing significant threats to functional status. Comorbid cardiovascular disease, emotional vulnerability, peripheral and respiratory muscle wasting, and sedentary, socially isolated lifestyle contribute to impaired function as COPD progresses (Carrieri-Kohlman et al., 2010; Monjazebi et al., 2016). Concomitant effects of dyspnea and fatigue limit physical activity, leading to systematic deconditioning and limited function in daily life (Kapella et al., 2006). Poor functional status is a strong predictor of hospitalization and survival in COPD (Reardon et al., 2006). Optimization of physical function through self-management (e.g., symptom control, reducing exacerbations, and exercise) is critical to maintaining quality of life (Effing et al., 2016; Grodner et al., 1996; Guyatt et al., 2007; Liu et al., 2014) and best supported through formal pulmonary rehabilitation programming (Balkissoon et al., 2011; Bourbeau & van der Palen, 2009; Steer et al., 2010). Pulmonary rehabilitation professionals acknowledge that adequate patient activation is a necessary patient characteristic for regaining function through outpatient rehabilitation programming (Stoilkova-Hartmann, Janssen, Franssen, Spruit & Wouters, 2015). Supporting this assertion, Korpershoek et al. (2016) found that functional status was significantly correlated with patient activation level among people with COPD in their sample.

General Perception of Health

General perceptions of health reflect the subjective synthesis of all aspects of health, disease, the individual, and their environment (Ferrans et al., 2005; Wilson & Cleary, 1995). Integrated physiological and psychosocial factors influence how people living with COPD perceive and rate their health (Bentsen et al., 2008). Wilson and Cleary (1995) asserted that self-rated health was synonymous with general health perception. Thus, a single question asking,

“How would you rate your health—excellent, very good, good, fair, or poor?” provides a simple and global approach to assessing general perception of health (Ferrans et al., 2005).

The single question to assess general perception of health has been widely studied in COPD. Strong correlations have been identified between symptoms (i.e., dyspnea and fatigue) and general perception of health among adults with COPD (Mahler & Mackowiak, 1995; Nguyen et al., 2008). Further, diminished physical function from impaired respiration imposes negative effects on general perception of health (Nguyen et al., 2008). The global, single question assessing self-rated health is an important measure of risk for negative health outcomes in COPD. Self-reported health status of *fair* or *poor* was found to be an independent predictor of hospitalization based on multiple logistic regressions in among patients involved in the medical arm of the National Emphysema Treatment Trial (Benzo et al., 2010). The authors reported the odds of being hospitalized for COPD were 1.6 times greater among patients who rated their health *fair* or *poor* as compared to patients rating their health *good* or *very good* (Benzo et al., 2010). Further, self-rated health has been found to independently predict COPD-related mortality across diverse epidemiological samples and persists in multivariate models including potential confounders, such as medical, behavioral, and psychological risk factors (Benzo et al., 2010; Nguyen et al., 2008; Park and Larson, 2016; Wagner & Short, 2014).

General perceptions of health while living with COPD may influence self-management engagement (e.g., treatment adherence and coping) and thus, directly impact health outcomes (Lorig & Holman, 2003). Studies of determinants of patient activation revealed negative perception of health was associated with lower patient activation (Bos-Touwen et al., 2015; Chubak et al., 2012; Korpershoek et al., 2016) and positive perception of health with higher activation levels (Schmaderer et al., 2016). Rijken, Heijmans, Jansen and Rademakers (2014)

and Hibbard et al. (2015) found through longitudinal analyses that patient activation levels and self-rated health similarly decrease over time in the setting of chronic disease. Progressive deterioration of health and diminishing capacity to engage in self-management activities pose tangible risk factors for poor health outcomes for people living with COPD.

Overall Quality of Life

Per Ferrans (1990), quality of life is “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans, 1990, p.15). People with COPD report higher rates of poor overall quality of life as compared to other chronic conditions, including heart failure and chronic renal disease (Guyatt et al., 2007). The target of COPD treatments and rehabilitation is to improve or maintain quality of life (Celli et al., 2015).

Sexton, Munro, Chang, Woods, and Milde’s (1988) seminal work explored the problems women experienced when diagnosed with COPD and the influence of these on overall life satisfaction. The participants identified symptoms of: (a) breathlessness and fatigue, (b) disease management-induced stress, (c) loss of role identity and fluctuating functional capacity, and (d) declining health status as the most significant contributors to diminished life satisfaction (Sexton et al., 1988). Later, Hu and Meek (2005) conducted a descriptive correlational inquiry to examine the relationships among bio-physiological variables, symptoms status, and quality of life in men and women with COPD. Like Sexton et al., (1988), their findings suggested symptoms (breathlessness), impaired functional status, and negative mood (affect states) significantly and negatively impacted quality of life (Hu & Meek, 2005). Guyatt, Ferrans, and colleagues (2005) suggested that in the setting of COPD, all domains of the Wilson and Cleary

Model (Wilson & Cleary, 1995) integrate to influence the individual's perception of overall quality of life.

The patient activation literature showed inconsistent relationships between quality of life and level of activation. Several studies reported that patients, who indicated they had good quality of life, also had higher patient activation scores (Dixon et al., 2009; Goodworth et al., 2016; Hibbard et al., 2007, 2015; Mosen et al., 2007). It is unclear from the self-management literature if better quality of life was a motivating factor for patient activation, and thus self-management engagement, or if higher activation and subsequent self-management behaviors lead to the improved quality of life (Goodworth et al., 2016). Quality of life was notably absent as a variable of interest in Korpershoek et al.'s (2016) comprehensive examination of factors influencing patient activation level of people with COPD. Schmaderer et al. (2016) did include quality of life in their examination of patient activation determinants in people with multimorbidity, including COPD. However, they did not find a relationship between quality of life and patient activation level (Schmaderer et al., 2016). Regardless of the direction of integration and influence, the literature suggests patient activation and quality of life are likely related through self-management processes in chronic disease (Dixon et al., 2009).

Application and Adaptation of the Conceptual Framework

The literature provided evidence for the application and adaptation of the Wilson Cleary Model (Wilson & Cleary, 1995) and Revised Wilson Cleary Model (Ferrans et al., 2005) to examine health outcomes. The Wilson Cleary Model (Wilson & Cleary, 1995) has been widely applied in COPD health outcomes research, including predictive validity testing (Ade-Oshifogun, 2012; Arnold, Rancor, Koeter, de Jongste & Sandeman, 2005; Bentsen et al., 2008; Ngyen et al., 2008). Several studies used part of the model to guide correlational studies of

general perceptions of health among people with COPD. Bentsen et al. (2008) applied the model to identify determinants of self-rated health, while Ngyen et al. (2008) used the model to explicate relationships between symptoms, function, and self-rated health. Additionally, Arnold, et al. (2005) applied the model to examine health and personal factors that influenced subjective and objective general perceptions of health in people with COPD and coronary artery disease. Ade-Oshifogun (2012) tested the fit of the entire model to predict quality of life among people with COPD.

The literature revealed examples of studies that adapted the Revised Wilson Cleary Model (Ferrans et al., 2005) to study health outcomes relevant to COPD care. Zubritsky et al. (2013) adapted and expanded the model to examine impact of cognitive function and long-term social supports on quality of life in older adults with multimorbidity. Arbaje et al. (2008) modified the model to describe and predict relationships among individual (socioeconomic status) and environmental (home arrangement and living status) characteristics, and likelihood of early hospital readmission among community-dwelling older adults with chronic disease. Two studies tested the explanatory ability of the revised model to identify disease-specific predictors of quality of life in adults receiving acute care for chronic conditions (Kring & Crane, 2009; Saengsiri, Thanasilp & Preechawong, 2014). Both studies provided evidence of goodness of fit of the Revised Wilson Cleary Model (Ferrans et al., 2005) for comprehensive examinations of health phenomena important to the development of nursing interventions in supporting chronic disease. A weakness of the studies that adapted or utilized only selected domains of the conceptual models was the lack of rationale to explain why some domains were used and others not.

Wilson and Cleary (1995) noted the breadth of domains while Ferrans et al. (2005) asserted the fluidity of the model, increased the utility of the conceptual framework in examinations of relationships among health phenomena. Thus, the authors have encouraged adaptation for application in research. However, the causal relationships implied within the models require all domains to be included for examinations of model fit and predictive validity involving highly integrated health outcomes (Ferrans et al., 2005). The studies that tested the models included predictor variables from all model domains (Ade-Oshifogun, 2012; Kring & Crane, 2009; Saengsiri et al., 2014).

Significant Gaps in Knowledge

With the high disease burden, morbidity, and growing mortality associated with COPD in the United States, there is a significant need to understand factors that contribute to successful engagement in self-management. Descriptions of characteristics of study responders and assessments used to individualize interventions to meet participants' levels of self-management capability were missing from the self-management intervention literature. Patient activation has emerged as a critical concept in self-management science and predictor of health outcomes in chronic disease, yet has been minimally discussed in the COPD literature. One study described patient activation among people with COPD (Halding & Grov, 2017), and several did so in the context of COPD being a sub-cohort of larger chronic disease studies (Bos-Touwen et al., 2015; Greene & Hibbard, 2012; Hibbard et al., 2015; Hibbard et al., 2007; Turner, Anderson, Wallace & Kennedy-Williams, 2014). Notably, only one study examined COPD-related patient factors as determinants of patient activation in Dutch people with COPD (Korpershoek et al., 2016). This study addresses the gap by providing a comprehensive description of patient characteristics, health outcomes, and patient activation levels experienced by people living with COPD.

Fundamental theoretical knowledge of patient activation was missing from the literature. A theoretical or conceptual framework describing patient activation has not yet been published. Although Hibbard's (2004) definition is widely accepted as the only conceptual and operational definition of patient activation, concept analyses that examined patient activation or its use in nursing or other disciplines have not been reported in the literature. Also missing from the literature were theory generating, qualitative studies to explore the lived experience of chronically ill people with varying levels of patient activation.

The second aim of this dissertation research partly addressed the theoretical gap in patient activation literature through novel application of a health outcome conceptual model to examine the concept. Specifically, the Revised Wilson Cleary Model (Ferrans et al., 2005) framed the examination of relationships among patient characteristics, health outcomes, and patient activation level of people with COPD. Further research is required to establish understanding of the complexities of patient activation for people with specific chronic conditions.

The emerging literature that described determinants of patient activation level among people with chronic diseases illuminated relevant health factors and patient characteristics that could contribute to self-management risk assessment or intervention design. In the context of COPD, the results from the Dutch studies by Bos-Touwen et al. (2015) and Korpershoek et al. (2016) reflected predictive factors that were likely unique to the Netherlands' health care system, lifestyle factors, and environmental characteristics. Though informative, these findings could not be generalized to adults in the U.S. with COPD. The diversity of determinants of patient activation identified in the literature review was difficult to contextualize within the predominant models of chronic disease care. Some determinants reflected modifiable targets for self-management interventions, such as health literacy, self-efficacy, Body Mass Index, and self-rated

health. Others represented non-modifiable characteristics—most applicable to self-management risk assessment, including high comorbidity, limited social support, and negative affect states. Without an organizing framework to provide context to these findings, it was impossible to translate these findings to the current chronic care paradigm.

Findings from the third aim of this study begin to illuminate the independent patient and disease-specific predictors explaining the variance in patient activation level among U.S. adults living with COPD. These factors have not been described in the extant patient activation literature. Further, these determinants contribute to call from the COPD self-management research community to identify the unique patient characteristics necessary to self-manage.

Summary

This chapter provided a review and synthesis of the relevant theoretical and research literature related to self-management of COPD and patient activation. Empirical evidence demonstrated a positive association between patient activation, self-management, and health outcomes in chronic disease. The significance of self-management to achievement of treatment goals in COPD, most notably quality of life, underscores the importance of exploring patient activation in the lives of people with COPD. Further, the research priority of the COPD community to understand the patient characteristics necessary to effectively self-manage supported the examination of determinants of patient activation level in people with COPD.

CHAPTER III

METHODOLOGY

Introduction

The objective of this quantitative study was to describe and examine the relationships among patient characteristics and health outcome factors, as conceptualized in the Revised Wilson Cleary Model (Ferrans et al., 2005), as determinants of patient activation in adults with chronic obstructive pulmonary disease (COPD). The specific aims of this study were to: (a) describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of U.S. adults with COPD; (b) examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample; and (c) identify the independent predictors of patient activation in the sample.

This chapter presents the research design and procedures used in this dissertation study. A description of the participants, including the process of identification and recruitment of the study sample is offered. The measures, data management, and statistical procedures to achieve the study aims are presented. Finally, a discussion of ethical considerations to protect human subjects and limitations of the study are presented.

Research Design

This cross-sectional, descriptive correlational study was designed to explore the determinants of patient activation level among patient characteristics and health outcome variables experienced by people living with COPD. A cross-sectional design was chosen to assess and describe the status of multiple phenomena experienced by people at a single point in time (Polit & Beck, 2012). The descriptive correlational design allowed for description and examination of the relationships among several study variables, not logistically or ethically conducive to manipulation, within a single group (Curtis, Comisky & Dempsey, 2016; Grove et al., 2013). Consistent with the method, measurement of variables was largely accomplished through collection of self-reported data with a questionnaire. As causality was not the goal of this inquiry, a non-experimental design supported the comprehensive examination of the determinants of patient activation, yielding new insight into the relationships among patient characteristics and the capacity to self-manage COPD.

Population and Sample

Population Description

The Centers for Disease Control and Prevention estimate the prevalence of COPD in the United States to be between 4% and 12%, varying significantly by geographical region, race, ethnicity, and socioeconomic status (CDC, 2017). The best current estimate of race and ethnic distribution of the disease in the U.S. suggests multiracial and American Indian or Alaskan Natives are mostly affected, followed by Caucasian non-Hispanics and much smaller numbers of African Americans, Latinos, and Asian Americans or Pacific Islanders (CDC, 2017; Tilert et al., 2013). In addition, women now outnumber men diagnosed with COPD (CDC, 2017). COPD is a disease of middle-older adulthood, with symptoms of the condition typically presenting after 40

years of age and diagnosis after age 65 (CDC, 2017). The main cause of COPD in the United States continues to be tobacco smoking (NHLBI, 2013). Closely following cigarette smoking, environmental and occupational exposures, and childhood respiratory infections and genetics, which have been implicated as causal factors for COPD (GOLD, 2018). Recent statistics from the Centers for Disease Control suggest that COPD prevalence, morbidity requiring hospitalization, and death is significantly higher among people living in rural America than among those in urban areas (Croft et al., 2018).

Sample Description

A purposeful sampling design was used to obtain participants for the study. This design reflected a desire for a representative sample of adults living with COPD in the United States with minimal sampling error and limited systematic bias (Grove et al., 2013). Inclusion criteria were men and women who: (a) were 40 years of age or older, (b) had a clinical diagnosis of COPD, chronic bronchitis, or emphysema, (c) had completed spirometry at the study site, (d) were current or past smokers of at least 10 pack-years, (e) had a U.S. primary mailing address, (f) could speak and read the English language, and (g) could provide informed consent for participation in this study. Exclusion criteria included persons: (a) living in an assisted living or skilled nursing facility, (b) enrolled in adult complex care coordination programming, (c) were prisoners, or (d) had diagnosed cognitive disease or mental illness impairing ability to answer questions or provide informed consent.

The inclusion and exclusion criteria defined for this study were chosen to identify a representative sample of adults with COPD living in the United States able to engage in self-management activities. Participants were not excluded based on race or ethnicity. The age threshold of 40 years was established, as symptoms associated with COPD (e.g., dyspnea, cough,

excess sputum production) do not typically present before the age of 40 years (NHLBI, 2013). No upper age threshold was set for the study. Pregnant women could participate as this survey study posed minimal risk. Finally, children were not eligible to participate because the trajectory of exposures and impairment of lung function associated with COPD impacts only adults.

A sample of American adults who received care at one of three major Mayo Clinic campuses in the United States was sought for the study. The Mayo Clinic provides general medical and specialty care for a predominately U.S. patient population, though draws an international clientele as a known healthcare leader in the world. The Mayo Clinic campuses, located in the American Southwest, Midwest, and Southeast, offer comprehensive pulmonary care, including pulmonary function testing and radiological testing, associated the diagnosis and treatment of COPD.

Sampling Plan

The sample was obtained through use of Informatics for Integrating Biology and the Bedside (i2b2) supported by Grant Number UL1 TR002377 from the National Center for Advancing Translational Science. The i2b2 tool is a self-service, scalable informatics framework utilizing patient-oriented clinical data for various types and stages of research (<https://www.i2b2.org>). A i2b2 search query was developed based on searchable inclusion criteria of the study. The query, which included patient demographics, vital status, diagnoses, and spirometry procedures, yielded an adequate sample of 641 patients. After removing non-English speaking and international patients, random numbers were assigned to the remaining 574 patients of the accessible sample. The i2b2 output file was sorted in ascending order, using Microsoft Excel (Microsoft Office 365 Home 2016, Version 1804) functions to create a randomized list of patients. Electronic medical records of the first 350 patients in the sample

were reviewed for eligibility, including confirmation of COPD diagnosis and spirometry results, smoking history, indication of skilled care status, care coordination participation, and incarceration. A total of 250 eligible patients were approached via a mailed study packet.

Sample size. An a priori power analysis was conducted using G*Power 3 (G*Power 3 for Windows 8, Release 3.1.9.2) software for multiple linear regression (Faul, Erdfelder, Buchner & Lang, 2009). With a significance level of .05, 80% power, estimate of six predictor variables, and a conservative medium effect size of $f^2 = 0.15$, based on the work of Korpershoek et al. (2016), who reported a modest R^2 of 0.17, 98 participants were required. To account for attrition or incomplete data in the survey methodology, 20% was added to the power analysis results, yielding in a desired total sample size of approximately 120 participants.

Two hundred and fifty patients identified from the i2b2 search were approached for participation through the study mailing, described in detail later in this chapter. Eighty-eight patients responded to the study mailing. Twenty-three patients declined participation and six patients approached were noted to be deceased via letter, telephone, or email message from a family member to the PI. Fifty-nine surveys were returned. Three of these surveys were not included in the data analysis, as the participants did not accompany them with signed consent. In addition, eight completed surveys were included from the pilot study, increasing the total sample size to 64. The pilot study is described in detail later in this chapter.

Methods

Instrumentation

The instruments used to measure the variables in this study are presented as organized by the domains of the Revised Wilson Cleary Model (Ferrans et al., 2005). Characteristics of the individual, their environment, and their health outcomes (e.g., biological factors, symptoms,

functional status, general perception of health, overall quality of life) were measured as independent variables by tools with good validity and reliability in the population. The dependent variable patient activation was adapted to be examined within the Revised Wilson Cleary Model (Ferrans et al., 2005) and was measured with the Patient Activation Measure.

Characteristics of the Individual and the Environment

As defined by Ferrans et al. (2005), the collective characteristics of the individuals and their environment reflect the psychosocial, demographic, interpersonal, developmental, setting, and biological factors, which influence health and health outcomes of people living with chronic disease. For this study, psychological measures, specifically positive and negative affect, were measured by the Positive Affect Negative Affect Schedule (Watson, Clark & Tellegen, 1988). The demographic measures of age, gender, race, ethnicity, formal education, earned income level, and working status were assessed. Biological measures included the following self-reported variables: (a) height and weight to calculate Body Mass Index , (b) health care utilization (i.e., number of visits to an emergency department due to breathing problems and number of visits to a primary care provider for breathing problems in the past 12 months), (c) smoking status and history (i.e., current or former smoker and total pack-years), and (d) time since diagnosis of COPD. Characteristics of the environment were assessed with the following independent variables: (a) category of residence (rural or urban), (b) marital status (single, married/committed relationship, separated/divorced, or widowed), and (c) living status (alone or with others).

Demographic form. Individual and environmental characteristic variables were assessed through self-reported responses on the demographic form. Age was reported in years, at time of questionnaire completion. Race and ethnicity were assessed using 2013 United States

Census Bureau Questionnaire categories (U.S. Department of Commerce, United States Census Bureau, 2013a). Marital status was identified based on six categories: married, civil union/domestic partnership, widowed, living with significant other, single (never married), and divorced/separated. The reported highest completed formal education program reflected educational level. Participants chose one of the following to reflect employment status: (a) currently working, (b) on leave of absence, (c) retired (not because of ill health), (d) disabled and/or retired because of ill health, (e) homemaker, and (f) unemployed to assess employment status, consistent with the 2013 United States Census Bureau Questionnaire categories (U.S. Department of Commerce, United States Census Bureau, 2013b). Self-report of total household income from all sources in the past year reflected their annual earned income (U.S. Department of Commerce, United States Census Bureau, 2016). The total number of years since diagnosis of COPD was captured through response to the choices of 0-3 years, 3-10 years, and greater than 10 years, consistent with prior studies of determinants of patient activation in COPD (Korpershoek et al., 2016). Primary care and emergency department visits because of breathing problems in the past 12 months were recorded. Smoking history of participants was assessed by asking if they were: (a) current or former smokers (of cigarettes and/or pipes), (b) the average number of cigarettes/pipes smoked per day, while smoking, and (c) the total number of years as a smoker. These values were used to calculate smoking pack-years per the GOLD Guidelines (GOLD, 2018).

Participant response to the question, “Who do you live with—alone or with family or friends?” reflected their current living status. The United States Census Bureau defines rural as what is not urban (Ratcliffe, Burd, Holder & Fields, 2016). Thus, congruent with the 2010 Census categorization of residence, participants were asked to indicate if their residence was in a

community/outlying area of less than 50,000 residents (rural) or greater than 50,000 residents (urban) (U.S. Department of Commerce, United States Census Bureau, 2012). See Appendix E for the demographic form.

Positive and negative affect schedule (PANAS). PANAS (Watson, Clark & Tellegen, 1988) is a 20-item self-report measure designed to evaluate the extent individuals experience a range of positive and negative affect states. See Appendix A. Ten positive adjectives and 10 negative adjectives are presented with respondent instructions to indicate how much each of the adjective items had been experienced, using a 5-point Likert scale (1 = very slightly, 5 = very much). As affect can be both a mood trait (dispositional) and a state concept (situational), the PANAS is robust in measuring both forms of affect by allowing investigators to choose the time frame to assess either (Merz & Roesch, 2011). For this study, the mood trait or dispositional nature of participant's positive and negative affect was of interest and assessed by asking the participants to respond to items with the time period of "in the past month" (Watson, et al., 1988).

Scoring and administration. Positive and negative affect scores (interval level data) were calculated by summing responses in each domain (Watson et al., 1988). Scores in each domain can range from 10 to 50, with higher domain scores reflecting greater affect level. Responding to the 20 items of the paper-and-pencil test took approximately five minutes. PANAS is a publicly accessible tool, free for clinical and research use (Crawford & Henry, 2004).

Psychometrics. Initial reliability and validity testing by Watson, Clark and Tellegen (1988) yielded correlation coefficients of .86 for the positive affect sub-domain and .87 negative affect sub-domain in a general population sample. Subsequent validity and reliability

examinations in healthy samples yielded fit indices of 0.94 and sub-domain correlation coefficients ranging from .80 to .92 (Crawford & Henry, 2004; Merz & Roesch, 2011). Further, Crawford and Henry (2004) reported minimal influence of demographic variables (i.e., age, gender, income level) on PANAS sub-domain scores, suggesting stability and reliability of the tool across demographic groups. Hu and Gruber (2008) reported excellent internal consistency values of $\alpha = .86$ and $.83$ for the positive and negative affect subscales, respectively, in older adults with multiple chronic conditions, including COPD. In this dissertation study the Cronbach's alpha for the total tool was $.761$ and the positive and negative affect subscales were $.923$ and $.870$, respectively.

PANAS is frequently cited in COPD outcomes research describing relationships between dyspnea and mood (Carrieri-Kohlman et al., 2010) and affect and quality of life (Benzo et al., 2016) of those with the disease. The PANAS was appropriate for the goals of this study because of: (a) good to excellent reliability and validity of the PANAS in chronic disease studies, (b) established use in COPD research, and (c) simplicity of response by participants.

Biological Function

Biological function represents the molecular, cellular, and whole organ system processes that support life and is operationalized through measures to assess and diagnose organ function (Ferrans et al., 2005). The gold standard for COPD diagnosis is the measurement of large and small airway obstruction in the lungs using spirometry (GOLD, 2018). Spirometry results, specifically the most recent post-bronchodilator forced expiratory volume (FEV_1) value and ratio of forced expiratory volume (FEV_1) to forced vital capacity volume (FVC), were abstracted from the electronic medical record of participants to measure this domain.

Spirometry. Spirometry is a physiological test to measure how an individual inhales and exhales volumes of air over a function of time (Miller et al., 2005). The standardized assessment yields objective measures of health or dysfunction of the lungs and airways. The American Thoracic Society and European Respiratory Society Task Force published a standardized spirometry guideline in 2005. The guideline outlines standards for equipment, technical factors, and age, gender, and race norms for outcomes (Miller et al., 2005). At the study site the guideline is used to obtain spirometric measures of forced expiratory volume (FEV_1), the volume of air in the first second of forceful exhalation, and forced vital capacity (FVC), the largest volume of forcefully exhaled air following maximum inspiration. The ratio of these values reflects the degree of airway obstruction. A $FEV_1/FVC < 0.70$ and $FEV_1 < 80\%$ of the predicted value for age, gender, and race, are required elements for diagnosis of COPD (GOLD, 2018).

COPD severity was categorized based on standardized spirometry criteria established by the Global Strategy for the Diagnosis, Management and Prevention of COPD (GOLD) (GOLD, 2018). GOLD classifies COPD in four stages: (a) COPD stage 1: mild ($FEV_1/FVC < 0.70$, $FEV_1 < 80\%$ predicted), (b) COPD stage 2: moderate ($FEV_1/FVC < 0.70$, $FEV_1 50-80\%$ predicted), (c) COPD stage 3: severe ($FEV_1/FVC < 0.70$, $FEV_1 30-50\%$ predicted), and (d) COPD stage 4: very severe ($FEV_1/FVC < 0.70$, $FEV_1 < 30\%$ predicted) (GOLD, 2018). The FEV_1 and $FEV_1\%$ predicted (continuous-level data) were abstracted from the medical record. The FEV_1/FVC values of each participant were verified to meet the benchmark of < 0.70 for calculation of categorical stage of COPD severity with the $FEV_1\%$ predicted values.

Symptoms

Symptoms reflect the abnormal physical, emotional, or cognitive state experienced by persons with chronic disease (Ferrans et al., 2005). Perception of symptoms is a key patient outcome measure, as chronic diseases are managed, not cured (Redman, 2007). Dyspnea and fatigue are pervasive symptoms experienced by people with COPD. The negative impact of these symptoms on quality of life is the reason they are the primary foci of medical and self-management interventions (Kaptein et al., 2014). The symptoms domain of the model was measured with the Pulmonary Functional Status and Dyspnea Questionnaire-Modified (PFSDQ-M) dyspnea and fatigue sub-scales (Lareau, Meek & Roos, 1998). Discussion of the PFSDQ-M psychometrics is presented in the following section, Functional Status.

Functional Status

Ferrans et al. (2005) defined the concept of functional status as a person's ability to perform tasks in multiple domains of his/her life, reflecting adequate physical, social, role and emotional capacity. In both clinical and empirical literature, the gold standard criterion for assessment of functional status in COPD is exercise capacity measured by a standardized exercise test (Monjazebi et al., 2016). Thus, an emphasis is placed on one's physical capacity to carry out the task of walking, minimizing the multidimensional capacity needed to engage in the many facets of daily life. For this study, the robust Pulmonary Functional Status and Dyspnea Questionnaire-Modified (Lareau, Meek & Roos, 1998) was chosen to quantify the level of overall functional status. It addresses both the physiological impact of COPD (muscle weakness, limited energy capital, and decreased stamina) and the role-limiting effects of symptoms on engaging the basic activities of daily life. Consistent with Ferrans' definition, this tool measures independent functional status while engaging in multiple domains of daily life. Further, it

assesses walking activity and is thus congruent with the predominate emphasis on walking function in the COPD literature.

Pulmonary functional status and dyspnea questionnaire-modified (PFSDQ-M). The Pulmonary Functional Status and Dyspnea Questionnaire-Modified (PFSDQ-M) (Lareau et al., 1998) is a disease specific, self-administered instrument designed to assess the change in ability to carry out common daily activities. The activities include bathing, dressing, walking, negotiating unlevel terrain and stairs, and preparing food, currently as compared to before the onset of the physiological and symptom impact of chronic lung disease. See the PFSDQ-M in Appendix B. This self-report tool of 40 questions is a modification from the original 167-question Pulmonary Functional Status and Dyspnea Questionnaire (Lareau et al., 1998). This version includes activities common to most adults with breathing difficulties and has fewer questions, decreasing survey burden. The PFSDQ-M takes less than 10 minutes to complete and requires reading skills at the 6th-7th-grade level, consistent with reasonable literacy standards and time burden for questionnaire response (Creswell, 2014).

Scoring. For each component, dyspnea, fatigue, and change in activities of living since diagnosis, ratings are noted on an 11-point Likert scale ranging from 0 to 10. For the symptom components qualifiers of “No shortness of breath/fatigue” equal to 0 and “Very severe shortness of breath/fatigue” equal to 10 are presented to orient responses. The change in activity component scales also have qualifiers, for example, “As active as I have ever been” on the 0 end of the scale to “Have omitted doing (the activity) entirely” on the 10 end of the scale. For each of the three components scores are calculated with sums ranging between 0 and 100, lower scores indicating better functional status or lower symptom impact. Further, sub-scale component scores and total scores can be categorized by tertiles of 1-3 mild, 4-6 moderate, and 7-9 severe.

The total score for the Dyspnea sub-scale and total score for the Fatigue sub-scale (ratio level data) represented the symptom domain measure of the Revised Wilson Cleary Model (Ferrans et al, 2005). The total score for the activity sub-scale provided a measure of overall functional status from the model.

Psychometrics. Reliability of the PFSDQ-M was established through test-retest intraclass correlation coefficient of .93 (Kovelis et al., 2008). Internal consistency and convergent validity of the PFSDQ-M total score, dyspnea sub-score, fatigue sub-score, and change in activity sub-score was supported by reported high Cronbach α of .93 to .95 when the instrument is tested against the St. Georges Respiratory Questionnaire, Medical Research Council Scale (Kovelis et al., 2008), and London Chest Activity of Daily Living Scale (Kovelis et al., 2011) in older adults (mean age > 65 years) with stable moderate to severe COPD. Further, as a measure of dyspnea, sensitivity of discrimination of dyspnea scores in people with mild to severe COPD was demonstrated through significant correlations with FEV₁, FEV₁ (% predicted), FVC (% predicted), FEV₁/FVC and partial pressure of oxygen (Regueiro, et al., 2013). In this dissertation study, internal consistency was similarly high for the PFSDQ-M with a Cronbach's α for the dyspnea sub score of .946, fatigue sub score of .940, and activity sub score of .943.

General Health Perceptions

General perception of health is a uniquely perceived, multidimensional representation of an individual's evaluation of their overall health status (Ferrans et al., 2005). Consistent with the recommendations of Ferrans et al. (2005), general perception of health was operationalized for this study by a single question from the general perception of health domain within the Medical Outcomes Study SF-36 (Ware & Sherbourne, 1992).

Single question from medical outcomes study SF-36. The global question from the Medical Outcomes Study SF-36 assessed general perception of health by asking, “In general, would you say your health is: excellent, very good, good, fair or poor?” (Ware & Sherbourne, 1992). See Appendix D. Use of the single question within clinical or research settings for assessment of self-rated health assessment does not require license for use (Ware & Sherbourne, 1992).

Scoring. Respondents chose from one of the five levels to answer the question: excellent (5), very good (4), good (3), fair (2), or poor (1). Responses were dichotomized (nominal level data) and coded with 0 for those choosing “very/good” or “excellent” and 1 for “fair” or “poor” respectively, in accordance with previous studies (Nguyen et al., 2008). The single question is accessible in the public domain and requires only seconds to respond to when included in survey tools (Wagner & Short, 2014).

Psychometrics. Internal consistency of this single question from the SF-36 to measure general perception of health in people with chronic disease, including COPD, has been reported with Cronbach’s alpha of .78-.93 (Brazier et al., 1992; Wagner & Short, 2014; Ware & Sherbourne, 1992). Convergent validity established by correlations between this question and other measures of general perception of health has been reported with the General Health Rating Index $r = .96$ (Ware & Sherbourne, 1992) and the Nottingham Health Profile, $r = .87$ (Brazier et al., 1992). Internal consistency was not calculated for this single item within this dissertation study.

Overall Quality of Life

Overall quality of life is characterized as the subjective, multidimensional measure of well being and satisfaction of one’s life with chronic disease (Ferrans et al., 2005). Overall

quality of life anchors the Revised Wilson and Cleary Model of Health-related Quality of Life (Ferrans et al., 2005) as the most complex health outcome, reflecting integration of all health outcomes and patient characteristics preceding it. In 1990 Ferrans published a conceptual framework of quality of life that described the domains of health and functioning, social and economic, psychological and spiritual, and family as integral to overall quality of life. Ferrans et al. (2005) applied these domains to clarify and expand the conceptual definitions of characteristics of the individual and characteristics of the environment in their revision of the Wilson and Cleary Model. The disease-specific version of the Quality of Life Index-Pulmonary Version III (Ferrans & Powers, 1985) was chosen to provide a conceptually grounded measure of the health outcome overall quality of life in this study. This tool presents a structure of assessing overall quality of life congruent with Ferrans' conceptual definition of quality of life, "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (Ferrans, 1990, p. 15).

Quality of life index-pulmonary version III (QLI-P). The QLI-P (Ferrans & Powers, 1985) is a self-report instrument comprised of 36-paired questions assessing personal satisfaction and importance of various aspects of life. Importance ratings are used to weight satisfaction responses so that the scores reflect the respondent's satisfaction with the aspects of life they value the most (Ferrans & Powers, 1985). This instrument assesses importance and satisfaction within four life domains to provide an objective measure of overall quality of life. A common set of life items form the basis of the tool, with pulmonary-specific items inquiring about symptom (e.g., dyspnea, coughing, fatigue) impact on life. Respondents chose the degree of satisfaction and importance for each of the presented aspects of life, measured on a 6-point Likert scale with

1 meaning “very dissatisfied/unimportant,” and 6 meaning “very satisfied/important.” See Appendix C for the QLI-P.

Scoring and administration. The possible range for the total quality of life score is 0 to 30, with higher scores indicating a higher overall quality of life. While sub-scale scores for each domain could be calculated, the total score was used to operationalize overall quality of life for analyses. The instrument is written at the fourth-grade reading level (Ferrans & Powers, 1985) and was free to use for non-profit research (qli.org.uic.edu, n.d.).

Psychometrics. Internal consistency reliability for the QLI total score across adult age groups (Ferrans & Powers, 1985; Nesbitt & Heidrich, 2000), healthy subjects (Ferrans & Powers, 1985; Scott, 2000) and those with chronic diseases (Ozer & Efe, 2006; Scott et al., 2004), has been supported by Cronbach’s alphas ranging from .89 to .93. Extensive empirical literature review of factors related to quality of life generated the common and disease-specific questionnaire items and established the content validity of the QLI and QLI-P (qli.org.uic.edu, n.d.). Construct validity of the QLI is supported by strong correlations between the total score and life satisfaction ($r = .93$) (Ferrans & Powers, 1985, 1992) and factor analysis of each of the four domains explaining 91% of the total variance of quality of life (Ferrans & Powers, 1992). A limitation of this tool was the lack of reliability and validity reporting among adults with COPD. For this dissertation study, the Cronbach’s alpha of the QLI-P total score was high at .908.

Patient Activation Level

Patient activation is a measure of self-management capacity, operationally defined as the belief an individual has an important role to play in their health, demonstrated through the knowledge, skills, and confidence to maintain function, response to health changes, and access appropriate care for their health needs (Hibbard et al., 2004). The Patient Activation Measure

(PAM) (Hibbard, et al., 2004) objectively characterizes an individual's activation level on a spectrum of passive care receiver with limited self-management capacity (Level 1) to confident, capable, and engaged self-manager (Level 4) (Hibbard et al., 2004). Patient activation was operationalized for this study by the Patient Activation Measure-13 (Hibbard et al., 2005). Due to copyright restrictions, the PAM-13 is not included in the appendices.

Patient activation measure-13. PAM-13 is an interval-level, unidimensional, Guttman-like scale assessing an individual's knowledge, skills, and confidence for self-management in chronic disease. This tool was developed and tested by Hibbard and colleagues (Hibbard, Stockard et al., 2004; Hibbard, Mahoney et al., 2005). The PAM aims to assess cognitive and psychological variables through patient self-report of agreement or disagreement with 13 escalating statements on confidence, skills, beliefs, and knowledge related to personal health maintenance (Hibbard et al., 2004).

Scoring. The PAM-13 was administered as a self-report, paper-and-pencil questionnaire and took approximately 10 minutes to complete. Responses fall on a 4-point Likert scale (disagree strongly to agree strongly). Summation of responses generated a raw score that was converted to a continuous activation score (ranging from 0-100) (Hibbard et al., 2004). Further, scores were grouped into four hierarchical levels of health activation: (a) PAM level 1 (≤ 47.0), reflects an overwhelmed, passive recipient of care, (b) PAM level 2 (47.1 – 55.1) represents a lack of knowledge and necessary confidence to engage in self-management, (c) PAM level 3 (55.2 – 67.0) shows an individual beginning to engage, but needs support to learn new skills and maintain behaviors, and (d) PAM level 4 (≥ 67.1) reflects an active self-manager who may need support in times of stress (Hibbard et al., 2004). The PAM-13 was licensed for this dissertation study from Insignia Health, Inc. (<http://www.insigniahealth.com/>). See Appendix M.

Psychometrics. Numerous research studies across diverse health populations and adult ages have shown PAM-13 to be valid and reliable (Fowles et al., 2009; Hibbard et al., 2015; Hibbard & Tusler, 2007; Skolasky et al., 2011). In development and testing of a measure of patient activation, Rasch person reliability was satisfactory at .85 (Grove et al., 2013; Hibbard, Stockard et al., 2004; Hibbard, Mahoney et al., 2005). Good internal consistency of the 22-item and 13-item versions of the PAM was reflected by a Cronbach's alpha of .87 (Hibbard, Stockard et al., 2004; Hibbard, Mahoney et al., 2005). Content validity of the PAM to adequately measure the complex construct activation was established through an expert panel, reflecting diverse utilization of health activation in human functioning, consensus followed by patient focus group consensus for final item content and development of a conceptual activation definition (Hibbard et al., 2004).

Skolasky et al. (2011) explored increased age and multimorbidity among community-dwelling older adults within a group health organization to examine the construct validity of PAM for clinical use. Consistent with Hibbard et al. (Hibbard, Stockard et al., 2004; Hibbard, Mahoney et al., 2005), Skolasky and colleagues found high internal consistency of the items on the PAM-13 with a Cronbach's alpha of .87 in the subgroups examined. Fowles et al. (2009) further validated the PAM in a randomized trial of two health promotion programs within a large midwestern health maintenance organization. The study population reflected a diverse demographic sample of adults in two different work environments with varied health risk factors and health status. Rasch person reliability for each group was .83 and high internal consistency was noted with a Cronbach's alpha of .90 (Fowles et al., 2009). Lower item reliability was noted in the no chronic disease, age greater than 85 years, lower socio-economic status, and low self-reported health subgroups (Hibbard et al., 2005). Subsequent studies with these subgroups have

shown the internal consistency of PAM-13 items to be valid and reliable (Hibbard & Mahoney, 2010; Skolasky et al., 2011). In this dissertation study, the Cronbach's alpha for the PAM-13 was .893, consistent and slightly higher than the original work of Hibbard and colleagues in 2005. A summary table organizing the research variables as presented in the Revised Wilson Cleary conceptual model is presented in Figure 3.

Model Domain: Biological Factors		
Independent Variables	Instrument/Measure	Level of Measurement
Lung function	Spirometry results (FEV ₁ and FEV ₁ % Predicted)	Ratio
	GOLD categorization of COPD severity	Ordinal
Model Domain: Symptoms		
Independent Variables	Instrument/Measure	Level of Measurement
Dyspnea	Pulmonary Functional Status and Dyspnea Questionnaire: Dyspnea subscale score	Ratio
Fatigue	Pulmonary Functional Status and Dyspnea Questionnaire: Fatigue subscale score	Ratio
Model Domain: Functional Status		
Independent Variables	Instrument/Measure	Level of Measurement
Functional status	Pulmonary Functional Status and Dyspnea Questionnaire: Total Score	Ratio
Model Domain: General Perception of Health		
Independent Variables	Instrument/Measure	Level of Measurement
General perception of health	Single question of self-rated health from Medical Outcomes Study SF-36	Ordinal
Model Domain: Overall Quality of Life		
Independent Variables	Instrument/Measure	Level of Measurement
Overall quality of life	Quality of Life Index- Pulmonary Version III	Ratio
Model Domain: Individual Characteristics		
Independent Variables	Instrument/Measure	Level of Measurement
Age, gender, race, ethnicity, educational level, earned income level, employment	Demographic questions	Nominal, Ordinal, Interval, Ratio
Affect (Positive and Negative)	Positive and Negative Affect Scale	Interval
Health care utilization	Demographic questions	Nominal
Smoking history (current or former smoker, pack-years)	Demographic questions	Nominal/Ratio
Height and weight	*Body Mass Index (BMI) calculated from self-reported height and weight	Ratio
Duration of COPD	*Duration of COPD reflected self-reported total number of years since COPD diagnosis	Ordinal

Figure 3. Research Variable Table. Adapted from the Revised Wilson Cleary Model (Ferrans et al., 2005).

Figure 3. cont.

Model Domain: Environmental Characteristics		
Independent Variables	Instrument/Measure	Level of Measurement
Living situation (alone or with others), residence (rural vs. urban), marital status (single, married/committed relationship, separated/divorced, or widowed)	Demographic questions	Nominal
Additional Model Domain: Patient Activation Level		
Dependent Variable	Measure	Level of Measurement
Patient Activation	Patient Activation Measure-13	Ratio

Figure 3. Research Variable Table. Adapted from the Revised Wilson Cleary Model (Ferrans et al., 2005).

Pilot Study

Prior to implementing the survey study at Mayo Clinic, a pilot study was conducted to assess clarity of the questionnaire developed for data collection and the time needed to complete the tool. The University of North Dakota Institutional Review Board (IRB) and the American Lung Association Better Breather’s Clubs of the Twin Cities (ALAMN-BBC) provided ethical and conduct approval of the pilot study. The principal investigator (PI) introduced the study at the end of a regularly scheduled ALAMN-BBC meeting and the twelve attending members were invited to participate in the anonymous survey. An IRB-approved Informed Consent Statement, survey, and a postage-paid return envelope were provided to a convenience sample of nine attendees who expressed interest in participating. The survey tool included three additional questions to assess clarity of specific questions, format of the survey tool, and the total time spent to complete the questionnaire. Eight people returned completed surveys. Based on their responses, small changes were made to the format to improve readability and clarity of the questionnaire. Most critically, the pilot study revealed that participant self-report of their

spirometry results, specifically FEV₁ and FEV₁ percent predicted, was difficult and would lead to high missingness in the data. Only three participants were able to self-report one of two necessary spirometry values to assess degree of obstruction and disease severity. As central variables to examine biological function within the conceptual model and common elements in COPD research to meaningfully describe disease severity of study samples, it was necessary to identify another way to obtain spirometry data. Therefore, the decision was made to partner with healthcare organization for participant recruitment and data collection of spirometry values for the study.

Data Collection

The primary data collection method was participant completion of a self-report questionnaire. Questionnaires are a direct, cost-effective method of collecting self-report data from a geographically dispersed sample (Waltz et al., 2010). Standardization within a questionnaire format and ability to answer questions in the privacy of one's own home, "supports increased reliability of responses, facilitates comparison across respondents, and removes interviewer bias as a threat to validity" (Waltz et al., 2010, p. 308). The study questionnaire included the instruments described previously: (a) demographic form, (b) Pulmonary Functional Status and Dyspnea Questionnaire-Modified, (d) single question from the Medical Outcomes Study Short-form 36 to assess self-rated health, (e) Quality of Life Index-Pulmonary Version III, and (f) Patient Activation Measure-13. Data from the pilot study suggested the 160-item questionnaire took approximately 25 minutes to complete. Additionally, the most recent spirometry results were abstracted from the medical record.

Based on the principal investigator's prior survey research experience of older adults with chronic disease, a preference for paper-pencil questionnaires potentially existed among

participants. Instructions for questionnaire completion, including the option to contact the study team for telephone administration of the questionnaire, were included in the study introduction letter. It was expected that participants with visual impairments or low literacy requesting to complete questions over the telephone would be a rare occurrence and represent a small percentage of the data collected. Only one participant requested to complete the questionnaire by telephone.

Survey Methodology

The three-phase, Dillman Total Design Method (Dillman, 1978; Dillman et al., 2014) of survey research was employed to achieve an optimal survey return rate for this study. The Dillman Method proposes an 80% return rate for survey research (Dillman et al., 2014). With all factors held constant, the higher the response to a survey, the more likely the data will be representative of the population that was sampled (Grove et al., 2013). The step-wise Dillman Method begins with an initial mailing of a detailed introductory letter explaining the purpose of the study, a questionnaire printed in booklet style, and a postage-paid return envelope. All written communication to patients was formatted in a positive, appreciative tone using plain language and was IRB approved. Please see the Ethical Considerations section below for detail regarding the review process for the study documents. The contact letter clearly described the purpose of the study and was signed by the principal investigator by hand, in blue ink (Dillman, 1978). The questionnaire was formatted in booklet style with an illustrated front cover, included detailed instructions for completing the questions, and a unique respondent identifier (Dillman, 1978).

A pre-set pattern established the follow-up plan. Three weeks after the initial mailing non-responders were sent a reminder postcard. At six weeks after the initial mailing, the entire

study mailing was reissued to non-responders. Undeliverable paper questionnaires underwent address recheck for transcription error. The method frames the data collection process to a two-month period. The 250 study mailings were divided into 3 groups with the first sent in November of 2017, second in January of 2018, and final sent in February of 2018. The pattern described by Dillman (1978) was followed, yielding total time of data collection for each of the groups to 2 months.

Data management. Upon receipt of a completed questionnaire and signed Health Insurance Portability and Accountability Act of 1996 (HIPAA) authorization, the medical record was accessed for abstraction of the patient's most recent spirometry results. Participant questionnaire responses and spirometry data were entered into the Statistical Package for Social Sciences (SPSS) software (SPSS for Windows, Version 25). Accuracy of the final dataset was established through crosschecking of every fifth participant's questionnaire and spirometry report against the data file in SPSS.

Ethical Considerations

The study protocol was reviewed and approved by the Mayo Clinic and the University of North Dakota Institutional Review Board. The Mayo Clinic served as IRB of Record and the University of North Dakota served as Relying Organization for the ethical and regulatory oversight of the study. This study posed minimal risk to participants involving the use of a survey and abstraction of limited protected health information from the patient's medical record. All documents within the study mailing were Institutional Review Board approved. Please see Appendices H-J for the study contact letter, Health Insurance Portability and Accountability Act of 1996 (HIPAA) authorization, questionnaire, and reminder postcard. Contact letters sent to the identified sample were considered a form of oral consent by the IRB and (a) clearly identified the

voluntary, minimal risk nature of the study, (b) explained the expected benefits, (c) explained the right of participants to not answer any questions in the survey that made them uncomfortable, withdraw from the study at any time, or decline participation, (d) provided opportunity to request to participate in the study by telephone, and (e) provided contact information for the study team to ask questions about the research. The Health Insurance Portability and Accountability Act of 1996 authorizations (see Appendix J) were used to obtain informed consent for abstraction of limited protected health information, specifically spirometry results, from participants' medical records. All study personnel completed human subject protection training prior to initiation of the study.

Confidentiality and Data Security

All patient information and participant data were handled in a confidential manner. Confidentiality of the electronic dataset, comprised of entered questionnaire responses and spirometry results, was maintained using unique alphanumeric codes assigned to each study participant. Only the PI had access to the linking file, which associated patient identifiers with study identifiers. Further, data were secured through password protection of the electronic dataset and i2b2 output stored on a dedicated research computer server at the study site. Completed hard-copy questionnaires, signed HIPAA authorizations, and printed spirometry reports were kept in a locked file cabinet at the researcher's office at the study site, with access limited to the researcher and her site mentor. Participant data reported in this dissertation has been completed in aggregate to protect the anonymity of all participants involved in the study.

Data Analysis

Instrument scoring and psychometric testing was done prior to data analysis. The dataset was screened for missingness, outliers, and normality of variable distribution to meet the

assumptions of the univariate and multivariate analyses planned. All data analyses were conducted using the Statistical Package for the Social Sciences (SPSS for Windows, Version 25). Statistical significance (two-tailed) for data analysis was set at $p < 0.05$. The statistical consultant for this inquiry was included throughout database development, data preparation, and statistical analysis. Engaging the statistician throughout the research process ensured that the final data product was appropriate for analysis (Creswell, 2014).

Missing Data

Missing data is the single greatest threat to validity in survey research design (Creswell, 2014). Participants may have purposefully or inadvertently skipped or left questions blank within the study questionnaire. Frequencies were conducted to identify the extent of missing or unexpected values within the dataset. The amount and pattern of missing data, type of variable with missingness, and plan for handling the missing data is described.

One or more questions not answered within a multi-question tool were described as item nonresponse (Patrician, 2002). All questions missed in a multi-question tool or nonresponse to a single question variable measure was considered variable or unit nonresponse (Fox-Wasylyshyn & El-Masri, 2005; Patrician, 2002). Variable and unit nonresponse poses greater threat to losing statistical power through deletion of cases and introducing nonresponse bias to the data. Neither variable or unit nonresponse was found in the dataset.

The pattern of missing data points was established to identify the best approach to handling missing data (Shafer & Graham, 2002). Data missing at random (MAR) are values of data dependent upon other variables in the dataset (Allison, 2000). Data missing completely at random (MCAR) are values of data unique to the specific item and not related to other variables in the dataset (Patrician, 2002). The plan to handle the missing data included several processes

based on the type and pattern of missingness found, including sample mean substitution, case mean substitution, or hot-deck imputation. These processes could be utilized to impute best-fitting values from specific items or variables within the dataset (Fox-Wasylyshyn & El-Masri, 2005). Multiple imputation was also considered as a predictive technique utilizing iterative regression models to create “plausible imputations of missing values, to accurately reflect uncertainty, preserving important data relationships and aspects of the data distribution” (Patrician, 2002, p. 79). As it is difficult, if not impossible, to determine the mechanism of nonresponse in questionnaires, the advantages of multiple imputation’s ability to reflect uncertainty in missing data through incorporation of random error in the imputation process, may support use of the technique in addressing missingness for this analysis (Fox-Wasylyshyn & El-Masri, 2005; Patrician, 2002).

Overall, item and variable missingness was very low in the data set. For this dataset, the most appropriate single imputation technique to manage item missingness was case mean substitution. This method assumes that within an individual participant, known as a case, the item responses within a single tool or measure are closely related (Fox-Wasylyshyn & El-Masri, 2005). Item missingness was identified in responses for the PAM-13, PANAS, PFSDQ-M, and QLI-P, though insignificant at less than 5%. Per the scoring instructions for the PAM-13 (13 single question responses), case mean substitution was used to impute the data for missing values in among three cases for the dependent variable patient activation. Similarly, for missing case responses in the independent variables obtained from the PANAS (20 single question responses, 10 per subscale), PFSDQ-M (30 single questions, 10 per subscale), and the QLI-P (72 single questions), a mean for the subscale scores within each missing case was obtained and imputed for the missing value in the subscale.

Variable missingness was also low. Single datum was missing for the variables years of education, visits to a primary or pulmonary doctor, emergency department visits, Body Mass Index. Two data were missing from the variable smoking pack-years. The degree of missingness among these variables was insignificant at less than 5%, suggesting the pattern of missingness was random (Schafer & Graham, 2002). However, five data were missing for the key the spirometry variable measuring biological function, FEV₁, which was statistically significant (n = 5, 8%, t = -10.914, p < .001) indicating the data were missing not at random. It was important to carefully consider how to manage the data missing not at random to avoid invalidating the results (Fox-Wasylyshyn & El-Masri, 2005). In this study, the spirometry variable missingness was explained through the inclusion of pilot study participants, five of which who were unable to access their spirometry results, as described previously in the pilot study section of this chapter. Through significant, consideration was given to the reason for missingness, desire to maintain sample size, and likelihood that pilot participants were more similar than different to participants identified from the study site. The decision was made to not exclude these cases and to utilize sample mean substitution to manage the variable missingness. See Table 2 for the frequency and handling procedures of missingness for these variables.

Table 2. Variable Missingness and Handling Procedure

Variable	% Missing	Handling Procedure
FEV ₁ *	n = 5 (8%)	Sample Mean Substitution (<i>M</i> = 1.30)
Years of Education	n = 1 (3%)	Sample Mean Substitution (<i>M</i> = 3.5)
Pack years (smoking)	n = 2 (3%)	Sample Mean Substitution (<i>M</i> = 46)
MD visits	n = 1 (3%)	Sample Mean Substitution (<i>M</i> = 2)
ED Visits	n = 1 (3%)	Sample Mean Substitution (<i>M</i> = 1)
Body Mass Index	n = 1 (3%)	Sample Mean Substitution (<i>M</i> = 31)

Note: N = 64

*Though statistically significant, the pattern of missingness is explained by the inclusion of pilot study participants.

Outliers and Normality of Distribution

The dataset was evaluated for outlier cases by examining all continuous variables as standardized scores. Outliers are extreme scores, which can cause skewness violating the univariate assumption of normality of a variable's distribution (Tabachnick & Fidell, 2013). Single outlier scores were noted in the variables of FEV₁, negative affect sub score of the PANAS, fatigue symptom sub score of the PFSDQ-M, and Body Mass Index; two outlier scores found in the variable emergency department visits. Though the extreme cases were from the intended population, the variability of these values led to significant skewness and kurtosis of the variable distribution. Sample mean substitution was utilized to correct the extreme scores and maintain sample size.

Next, attention was paid to the distribution of the variables across the normal curve. In addition to visualizing the data in relation to their histograms, mathematical processes were applied to assess for skewness and kurtosis. Fisher's skewness coefficient was calculated for each continuous variable and evaluated against the critical value for a two-tailed standardized score. Fisher's coefficients greater than ± 3.26 were significantly skewed or kurtosed. Physician visits and emergency department visits demonstrated significant skewness and kurtosis. In addition, skewness was evident in the variables FEV₁, negative affect sub score, dyspnea sub score, fatigue sub score, and activity sub score. The level of skewness in these variables seemed to be inherent to the population, reflecting the unique impact of the disease on the individual living with COPD. To manage the skewness and kurtosis consideration was given to log transformation or categorization of the continuous variables. Several variables were not amenable to log transformation as they contained zero values, but negative affect was

successfully transformed via base-log arithmetic processes. Categorization of the skewed variables was rejected due to concerns regarding the small sample size of the study. If these variables were categorized and were found to be significantly associated with patient activation in the univariate analysis, they would require dummy variable creation for the multivariate regression. High numbers of dummy variables entered in linear regression analysis could make the resulting models unstable, raising questions regarding validity of the results (M. El-Masri, personal communication, April 25, 3018). Therefore, the decision was made to dichotomize the non-normally distributed variables. This was accomplished based on conceptual cut-off points congruent with each variable.

Data Analysis Description

Descriptive statistics were performed for each measured variable. Means, medians, modes, ranges, standard deviations, and frequency distributions were calculated and reported in tabular format. See Table 3. Significance for all data analyses was established by a two-tailed alpha of .05. A three-step statistical analysis process, outlined by the three study aims, is described below.

Specific aim #1. Describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of adults in the United States with COPD. To describe the patient characteristics of the sample, means and standard deviations were calculated for the continuous variables. These included earned income level, health care utilization, smoking pack years, Body Mass Index, positive affect and negative affect sub scores calculated from the PANAS, PFSDQ-M dyspnea, fatigue, and activity subscale scores, Quality of Life Index-Pulmonary Version III total score, and patient

activation score. Frequencies and percentages were calculated for the nominal and ordinal variables of age category, gender, race, ethnicity, educational level, working status, smoking history, living status, community size, duration of COPD diagnosis, and the single question from the Medical Outcomes Study SF-36 assessing general perception of health. Additionally, frequencies and percentages were calculated for the transformed variables that were dichotomized due to being non-normally distributed or containing greater than three levels of response.

Specific aim #2. Examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample. Univariate correlation statistics, specifically a series of Pearson correlation coefficient (r) calculations for continuous variables and one-way ANOVAs for categorical variables, were conducted to examine the presence, strength, and direction of relationships among each of the patient characteristics and the health outcomes as independent variables, and the outcome variable patient activation. Statistical significance for these tests was set at a liberal α of 0.25 (i.e., p value of $\leq .25$). Due to concerns regarding the small sample size, any categorical candidate variables (those with p value of $\leq .25$) with greater than three categories would be dichotomized, based on their frequency analysis, for entry into the subsequent multivariate regression analysis. One-way ANOVAs would be repeated to assess if the dichotomized variables retained significant association with the outcome variable.

Careful consideration was paid to two variables that raised concerns of conceptual confounding. Positive affect and negative affect are two concepts that are inversely related and as variables, posed risk of bivariate collinearity. If a participant had high positive affect, it would be expected that he/she would have low negative affect, as the relationship of one explains the

expected direction of the other. To address this concern, Kendal tau correlation coefficient was calculated using the non-normally distributed negative affect variable with positive affect. The result confirmed that negative affect has a non-statistically significant, negative association with positive affect ($\tau = -.42, p = .636$). In addition, log transformed negative affect was entered into a Pearson correlation coefficient calculation with positive affect, similarly resulting in a non-statistically significant, negative association ($r = -.036, p = .780$). Secondary to this analysis, the decision was made to only evaluate the positive affect variable in univariate and multivariate analysis to prevent potential confounding due to multicollinearity between positive and negative affect with patient activation.

Specific aim #3. Identify the independent predictors of patient activation in the sample. Stepwise linear regression analysis was performed to identify the independent predictors of patient activation. To minimize the potential of model inflation and to ensure a parsimonious model, only independent variables whose univariate test had a significant association with patient activation at alpha of 0.25 were included in the multivariate regression analysis (Hosmer & Lemeshow, 2001). The percentage of variance explained by the remaining independent variables ($R^2 \times 100$) was calculated and reported. Higher percentages suggest the significant relationships among the variables were true determinants of patient activation (Grove, 2007).

Several assumptions were verified to assure validity of the parametric linear regression analyses completed to meet Aim #3. Assumptions of linearity, normal distribution, and homoscedasticity were checked. Additionally, multivariate outliers and multicollinearity were considered among the significant univariate patient characteristics and health outcome variables entered into the regression model with patient activation (Grove, 2007). First, the relationships between the significant independent variables and the dependent variable were linear. Second,

the dependent variable patient activation, was normally distributed overall and for each of the independent variables (Kellar & Kelvin, 2013). Third, the distribution of patient activation scores was approximately equally distributed for each independent variable, thus meeting the assumption of homoscedasticity (Grove, 2007).

Multicollinearity, or high intercorrelation among the independent variables, is a significant threat in assessing complex, multidimensional health outcome variables (Curtis et al., 2016). To meet this assumption, tolerance levels and variance inflation factors were calculated for each independent variable to identify multicollinearity when all the variables are examined together. The higher the tolerance value, the less likely collinearity exists among the variables (Kellar & Kelvin, 2013). The variance inflation factor reflects how much of R^2 is inflated by multicollinearity (Mertler & Vannatta, 2002). Therefore, a tolerance value of less than .50 and a variance inflation factor greater than ten were used to identify multicollinearity of variables that required elimination from the regression models (Mertler & Vannatta, 2002). Condition indices that reflect the dependency of one variable on another in regression, were examined for values greater than 15 suggestive of collinearity and values greater than 30 indicatives of significant collinearity (Kellar & Kelvin, 2013).

Finally, exploration for the presence and influence of multivariate outliers was conducted. Multivariate outliers may exist between two or more variables or items among variables that when combined can raise or lower the variance explained by the predictor variables identified in linear regression (Kellar & Kelvin, 2013). Mahalanobis distance was calculated for each case to identify the presence of multivariate outliers then assessed for significance utilizing the χ^2 distribution, degrees of freedom equal to the number of independent variables in the model, and an α value of .001. Cook's distance was calculated to show whether

an outlier influenced the estimate variance explained by R^2 . A threshold of one was set for Cook's distance, values less than one, indicating the case was influential and should be deleted from the analysis.

Limitations

Careful consideration was given to the design of this study, including identification of potential challenges and limitations. The following subsections explain the limitations of self-report measures, selection bias, and the processes undertaken to minimize impact of these on the conduct and analysis of the study.

Self-Report

Self-reported measurement tools can pose inherent limitations on conceptual measures as they cannot be objectively verified (Lorig & Holman, 2003; Wilson & Cleary, 1995). Respondents may have over or under reported the significance of symptoms or perceptions of health, suffer from recall bias, or chose answers based on perceived social desirability when responding to the study questionnaire (Frank-Stromborg & Olsen, 2004; Grove, 2007). Nevertheless, the health outcome factors central to this study are personally experienced behavioral constructs (Ferrans et al., 2005). Wilson and Cleary (1995) acknowledged the measurement challenges of these factors and asserted self-report was necessary to obtain the lived perspective of the health outcomes within their model. The self-report measures chosen for this study were validated in adults with chronic disease, which contributed to the internal validity of the study.

Selection Bias

Selection bias and representativeness of the sample are concerns with survey methodology (Creswell, 2014). The accessible sample for this study was recruited from an

academic medical center with clinical sites in the Midwest, Southeast, and Southwest United States. People who received health care, specifically pulmonary care, at the study site may have different care and self-management experiences than other people living with COPD across the county. Survey research carries with it unique concerns regarding selection bias. Characteristics of patients agreeing to be part of this study, as opposed to those who declined or did not respond, are difficult to predict and may not adequately reflect the U.S. population of adults with COPD. Participants drawn from a study site with an internationally known research reputation may have been more interested in research in general, the study topic, or more activated than people from the general population (Hibbard et al., 2015). The primary objective of the study was to gain knowledge, not infer causality for generalization to the adult COPD population, thus drawing a sample from a large, national health care organization was appropriate for sampling in this cross-sectional, descriptive correlational design.

Language barrier. Inclusion of only adults who could read and speak English added an additional limitation associated with selection bias. The resulting sample was not entirely representative of the target population and further limits generalization of the results.

Homogeneity. Several individual characteristics and health outcome responses were homogeneous across the study sample. The differences in these factors between participants and patients who chose not to participate are unknown. Additionally, though the demographics of the study sample were consistent with many adults with COPD in the U.S., the lack of racial and ethnic diversity in the study sample further limits the generalizability of the results.

Summary

This chapter provided a detailed explanation of the methods and procedures followed to achieve the goals of this quantitative dissertation study. First, the COPD population of interest

and study setting were described. Next, sampling and recruitment plans described how the accessible sample was identified and obtained within the context of the larger population of interest. The sample size calculation to establish statistical significance in the subsequent data analyses was presented. The validity and reliability of the measurement tools, which comprised the study questionnaire and used to quantify the study variables derived from the Revised Wilson Clear Model (Ferrans et al., 2005), were presented. The data collection plan, guided by the Dillman Method (Dillman, 1978), data management processes to establish a complete, analyzable dataset, and efforts to protect human subjects and their protected health information were described. The chapter concluded with the data analysis plan used to address each of the three research aims and a discussion of limitations of the study.

CHAPTER IV

RESULTS

Introduction

The purpose of this study was to describe and examine the relationships among patient characteristics and health outcome factors, as conceptualized in the Revised Wilson Cleary Model (Ferrans et al., 2005), as determinants of patient activation in adults with COPD. The specific aims of the study were to:

1. Describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of adults in the United States with COPD.
2. Examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample.
3. Identify the independent predictors of patient activation in the sample.

This chapter presents the results of this dissertation study including the characteristics of the sample from which the data were derived, the descriptive and inferential statistical analyses to achieve the aims, and a summary of the results.

Analysis of Specific Aims

Specific Aim #1

The first aim of this dissertation study was to describe the patient characteristics, health outcome factors, and patient activation experienced by a cross-sectional sample of adults in the United States with COPD. Organized by the Revised Wilson Cleary Model (Ferrans et al., 2005), the patient characteristics were examined in the context of characteristics of the individuals and their environment. The health outcome factors were comprised of the biological function, symptoms, functional status, general health perceptions, and overall quality of life domains. The descriptive data representing the characteristics of the sample are presented, followed by the health outcome factors, and finally, the patient activation experienced by the sample.

Individual characteristics. The study sample was comprised of 64 adults who met inclusion criteria. The intervals of age for the study were set as follows: 40-50 years, 51-60 years, 61-70 years, 71-80 years, and 81 or more years of age. More than one-half ($n = 36, 56\%$) of the participants were between the ages of 71 and 80 years of age. Twenty-three percent of the sample ($n = 15$) reported their age between 61 and 70 years, followed by 11% ($n = 7$) reporting their age between 51 and 60 years. Nine percent ($n = 6$) were 81 years of age or older. The distribution of ages across the sample reflects the chronicity and impact of the disease on older adults (CDC, 2018). Though the index age for inclusion in the study was 40 years, based on the earliest typical onset of symptoms related to COPD, none of the patients less than 51 to 60 years of age approached to participate in the study did so. Almost two-thirds of the sample was women ($n = 39, 60.9\%$) compared to men ($n = 25, 39.1\%$). The sample was predominantly Caucasian ($n = 60, 94\%$), not Hispanic or Latino ($n = 62, 97\%$). Two participants (3%) reported being Black

or African American, one participant (2%) was American Indian/Alaskan Native, and one participant identified being more than one race (2%).

Understanding that COPD affects older adults, it was not surprising to find more than one-half ($n = 37$, 58%) of the sample indicated they were retired. Twenty-two percent ($n = 14$) of participants reported they were currently working outside of the home or were active homemakers ($n = 4$, 6%). Only nine (14%) participants indicated they were disabled or retired because of ill health.

The participants varied in their earned income levels. Fifty percent ($n = 32$) of the sample reported incomes greater than \$50,000 per year, while fourteen percent ($n = 9$) indicated they preferred not to answer the question assessing income level. The majority of participants attended or graduated from college including: completed some college or technical school training ($n = 26$, 41%), graduated from college ($n = 15$, 23%), and completed postgraduate degree ($n = 12$, 19%). Only 16% ($n = 10$) of the sample reported the highest level of education as graduating from high school or completing a GED.

The adults living with COPD who participated in this study varied in the length of time since first being diagnosed with the condition. Twelve individuals (19%) reported being newly diagnosed in the previous three years. The majority of participants ($n = 34$, 53%) lived with COPD for the past four to ten years. Almost one-third of the sample ($n = 18$, 28%) reported being diagnosed for more than ten years.

Lifetime tobacco exposure is quantified by a numerical value called a pack year. One pack year is defined as 20 cigarettes, the quantity of a package of cigarettes, smoked everyday for one year (GOLD, 2018). Pack years were calculated from participant report of the total number of years smoked, type of tobacco smoked (e.g., cigarettes, pipes, or cigars), and typical

quantity smoked per day. Only one participant reported smoking cigars, while the rest of the sample reported smoking cigarettes exclusively. The calculated pack years of the sample ranged from 10 to 100, with the mean pack years equal to smoking an average of two packs of cigarettes per day for 40 years ($M = 46.89$, $SD = 21.92$).

Assessment of affect was included in the domain of individual characteristics, per Ferrans et al.'s (2005) explication of psychological factors within this domain of the model. Participants were asked to respond to the PANAS questions in the context of the past month to understand their dispositional mood traits of positive or negative affect, rather than assess them on a given day to obtain a situational, more temporal response. The mean positive affect sub score of the sample was 32 ($SD = 8.86$), suggesting participants had a moderate level of dispositional positive affect. This means that they generally had a positive outlook on life. The mean negative affect sub score was low at 17 ($SD = 5.92$), indicating participants in the sample generally did not have negative dispositions. This result supports the conceptual view that one cannot have a high positive affect and a high negative affect at the same time.

Finally, Body Mass Index (BMI) was calculated to assess an individual characteristic with strong associations to health within illness and patient activation. Body Mass Index varied across the sample, however the mean BMI ($M = 29$, $SD 6.35$) indicated the sample trended toward being overweight. Excess body weight puts additional burden on the effort and sensation of breathing. The highest BMI of the sample was 44, which categorized the individual as having Class III Obesity (very severely obese) (WHO, 2018). On the other end of the BMI spectrum, the lowest calculated BMI of 18 reflected an underweight participant (WHO, 2018). Significant energy and caloric expenditure is needed to breathe with severe COPD, therefore it is not

uncommon for people to require assistance in maintaining weight through careful attention to nutrition (Celli et al., 2015).

Table 3. Individual Characteristics of Sample

Characteristics of the Individual	<i>n</i>	%
Age		
51-60	7	11
61-70	15	24
71-80	36	56
81 or more	6	9
Gender		
Female	39	61
Male	25	39
Ethnicity		
Not Hispanic or Latino	62	97
Unknown	2	3
Race		
American Indian/Alaskan Native	1	2
Black or African American	2	3
White	60	94
More than one race	1	2
Marital Status		
Married	39	61
Widowed	6	9
Living with a significant other	3	5
Single (never married)	2	3
Divorced/Separated	14	22
Educational Background		
Graduated high school or GED	10	16
Some college or technical school	26	41
Graduated college	15	23
Postgraduate school or degree	12	19
Not college educated [§]	37	58
College educated [§]	27	42

Table 3. cont.

Characteristics of the Individual	<i>n</i>	%		
Income				
Less than \$10,000	3	5		
\$10,000 to less than \$30,000	12	19		
\$30,000 to less than \$50,000	8	13		
\$50,000 to less than \$75,000	14	22		
\$75,000 to less than \$100,000	9	14		
\$100,000 or more	9	14		
I prefer not to answer this question	9	14		
Employment				
Currently working	14	22		
Retired (not because of ill health)	37	58		
Disabled and/or retired because of ill health	9	14		
Homemaker	4	6		
Years since diagnosis of COPD				
0-3 years	12	19		
4-10 years	34	53		
More than 10 years	18	28		
0-3 Years (Newly diagnosed) [§]	12	19		
4 or more than 10 years (Older diagnosis) [§]	52	81		
	Min	Max	Mean	<i>SD</i>
PANAS: Positive Affect	14	50	32.29	8.86
PANAS: Negative Affect [□]	10	32	15.64	5.92
Smoking: Pack Years	8	100	46.89	21.92
Body Mass Index	18	44	28.67	6.35

Note: N=64

§ Denotes transformed (dichotomized) variable values

□Base-e Log transformed Negative Affect (Min 2.3, Max 3.47, $M = 2.68$, $SD = .34$)

Environmental characteristics. Most participants ($n = 45$, 70%) reported living with family or friends. Two-thirds of the sample were married ($n = 39$, 61%) or lived with a significant other ($n = 3$, 5%). Thirty percent ($n = 19$) of the sample reported living alone. Of these, twenty-one percent ($n = 14$) indicated they were divorced or separated, 9% ($n = 6$) were widowed, and 3% ($n = 2$) reported being single, never married. The communities that

participants lived in were almost evenly split between urban and rural. Fifty-two percent ($n = 33$) of the sample indicated they lived in an urban setting of a community of more than 50,000 people while 48% ($n = 31$) of the sample reported living in a rural community of less than 50,000 people.

Table 4. Environmental Characteristics of Sample

Characteristics of the Environment	<i>n</i>	%
Living Arrangement		
Live alone	19	30
Live with others	45	70
Community Size		
Rural (Community of less than 50,000 people)	31	48
Urban (Community of more than 50,000 people)	33	52

Note: N = 64

Biological function. Spirometry measures are used to assess and diagnose lung function in COPD. The participants in this study had varying degrees of airway obstruction quantified and categorized by their spirometry values. The mean FEV₁ of the sample was 1.26 Liters/second ($SD = 0.59L/s$) and the mean FEV₁ percent predicted was 50.92 ($SD = 21.54$). The FEV₁ percent predicted values indicate how the patient's measured value (FEV₁) compares to the value the patient should have based on their age, height, gender, and ethnicity (GOLD, 2018). These values are used in concert with an FEV₁/FVC of less than 0.70 to classify the stage of severity of obstruction in COPD. Sixty-five percent of the sample had moderate (FEV₁ = 50-80% predicted [$n = 22$]) to severe (FEV₁ = 30-50% predicted [$n = 20$]) obstruction. On the opposite end of the distribution, 11% ($n = 7$) of the sample had mild (FEV₁ > 80% predicted) obstruction, while 17% ($n = 11$) had very severe (FEV₁ < 30% predicted) obstruction. Individuals with very severe

obstruction are often considered “end stage COPD” because of the dramatic limitation in airflow they experience (GOLD, 2018).

Table 5. Biological Function of Sample

Spirometry Values and Severity Staging	Min	Max	Mean	SD
FEV ₁ (Liters/second)	.32	2.98	1.26	.59
FEV ₁ percent predicted	15	119	50.92	21.54
<hr/>				
FEV ₁ [*]	<i>n</i>			%
1.5 Liters or greater	22			34
0.3 to 1.4 Liters (Low to Very low FEV ₁)	42			66
<hr/>				
Classification of COPD severity in patients with FEV ₁ / FVC < 0.70 ^{**}	<i>n</i>			%
Mild (FEV ₁ > 80% predicted)	7			11
Moderate (FEV ₁ = 50-80% predicted)	22			34
Severe (FEV ₁ = 30-50% predicted)	20			31
Very Severe (FEV ₁ < 30% predicted)	11			17

Note: N=64

* Categorized variable

** Classification of COPD severity based on the GOLD (2018) Criteria

Symptoms. Data for this model domain were analyzed from the PFSDQ-M Dyspnea and Fatigue subscales. Only one participant denied experiencing dyspnea or fatigue. Participants reported experiencing both symptoms regularly, but most indicated relatively low symptom burden evidenced by the mean dyspnea ($M = 23$, $SD = 19$) and fatigue ($M = 20$, $SD = 19$) scores. Scores ranged from zero indicating no dyspnea or fatigue to a high of 72 (dyspnea) and 71 (fatigue), respectively. Means, standard deviations, and ranges of each symptom were almost identical across the sample. High symptom burden did exist; 33% ($n = 21$) of the sample experienced moderate to severe dyspnea while only 23% ($n = 15$) experienced moderate to severe fatigue.

Table 6. Symptom Impact of the Sample

PFSDQ-M	Min	Max	Mean	SD
Dyspnea Sub score	0	72	23	19
Fatigue Sub score	0	71	20	19
Dyspnea Sub score [§]			<i>n</i>	%
Mild dyspnea [§]			43	67
Moderate to severe dyspnea [§]			21	33
Fatigue Sub score [§]			<i>n</i>	%
Mild fatigue [§]			49	77
Moderate to severe fatigue [§]			15	23

Note: N = 64

§ Denotes transformed (dichotomized) variable values

Functional status. The responses on the PFSDQ-M Activity subscale were similar to those found on the Dyspnea and Fatigue subscales. Most participants ($n = 48, 75\%$) reported a minor change ($M = 22, SD = 21$) in their functional status as compared to their pre-disease state. Participant total scores varied widely from 0 (No change in this activity) to 78 (Extreme change in this activity). Twenty-five percent of the sample ($M = 22, SD = 21$) experienced major changes in their functional status.

Table 7. Functional Status of the Sample

PFSDQ-M	Min	Max	Mean	SD
Activity Sub score	0	78	22	21
Activity Sub score [§]			<i>n</i>	%
Minor change in function [§]			48	75
Major change in function [§]			16	25

Note: N = 64

§ Denotes transformed (dichotomized) variable values

General perception of health. The global question from the Medical Outcomes Study SF-36 assessed general perception of health by asking, “In general, would you say your health is: excellent, very good, good, fair or poor?” (Ware & Sherbourne, 1992). Almost 60% of this sample chose Good ($n = 26$, 41%) or very good health ($n = 12$, 19%). The remaining 41% rated their health as fair ($n = 19$, 30%) or poor ($n = 7$, 11%). Even though most of the sample viewed their health positively, no participants chose “excellent” to rate their health.

Table 8. General Perception of Health of Sample

Single question from Medical Outcomes Study SF-36	<i>n</i>	%
Very Good	12	19
Good	26	41
Fair	19	30
Poor	7	11
Very Good or good [§]	38	59
Fair or poor [§]	26	41

Note: N = 64

§ Denotes transformed (dichotomized) variable values

Overall quality of life. Quality of life varied among the sample, as total scores ranged from 9 to 28 with higher scores indicating better quality of life. Overall, these participants perceived their quality of life to be moderately high as demonstrated by a mean total score of 20.56 ($SD = 4.50$).

Table 9. Overall Quality of Life of the Sample

QLI-P	Min	Max	Mean	<i>SD</i>
Overall Quality of Life	9	28	21	4.50

Note: N = 64

Patient activation. The Patient Activation Measure-13 measured the central concept of the study. Almost one-half of the sample was highly activated (Level 4, $n = 31$, 48%). Twenty-five percent ($n = 16$) of the sample scored in the range of Level 3, also considered activated (Hibbard et al., 2004). The remaining 25% of the sample were almost evenly split between the lower levels of activation. Fourteen percent ($n = 9$) of the sample was in Level 2 activation; Level 1 activated participants comprised the remaining 13% of the sample ($n = 8$).

Table 10. Patient Activation of the Sample

PAM-13	Mean	SD
PAM-13: Patient Activation Score	66	16
Patient Activation Levels	<i>n</i>	%
Level 1 (PAM score ≤ 47.0)	8	13
Level 2 (PAM score 47.1 to 55.1)	9	14
Level 3 (PAM score 55.2 to 67.0)	16	25
Level 4 (PAM score ≥ 67.1)	31	48

Note: N = 64

Specific Aim #2

The second aim of this study was to examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample. The relationships between the categorical and dichotomous variables from the model and the outcome variable, patient activation, were explored using one-way ANOVA, while Pearson product-moment correlations were calculated for continuous variables and patient activation. Statistical significance for these tests was set at a liberal α of 0.25 to identify candidate variables for inclusion in the regression analysis to address Specific Aim #3. The univariate statistical analyses were conducted to answer the primary question underpinning the aim, "What are the

presence, strength, and direction of relationships among the patient characteristics and health outcome factors with patient activation?”.

As described previously in Chapter III, categorical candidate variables (p value of $\leq .25$) with greater than three categories required dichotomization, based on their frequency analysis. These included: (a) general perception of health (good self-rated health [*very good* or *good*] and poor self-rated health [*fair* or *poor*]), (b) education level (college educated [completed college degree or postgraduate degree] and not college educated [high school/GED completion or some college or technical school]), and (c) time since diagnosis (newly diagnosed [0 to 3 years since diagnosis] and older diagnosis [4 or more years since diagnosis]). One-way ANOVAs were repeated and showed no change in the significance of the relationship after dichotomization of the variables. The final F statistics and significance are reported below. Independent variables with statistically significant relationships with patient activation are described in detail in Table 11.

Table 11. Relationships Between Independent Variables and Patient Activation Measure-13

Independent Variables	Univariate Analysis with Patient Activation	
Characteristics of the Individual	R	ANOVA
Age		F (3, 60) = 1.033
Gender		F (1, 62) = 1.554 [†]
Race		F (3, 60) = .590
Hispanic/Not Hispanic		F (1, 62) = .236
Ethnicity		F (1, 62) = .236
Marital Status		F (4, 59) = .493
Education [§]		F (1, 62) = 3.312 [†]
Income		F (5, 58) = .756
Employment		F (3, 60) = .708
Body Mass Index	$r (62) = -.221^{\dagger}$	
PANAS: Positive Affect	$r (62) = .519^{**}$	
Years since diagnosis of COPD [§]		F (1, 62) = 2.732 [†]
Pack years	$r (62) = .319^*$	

Table 11. cont.

Independent Variables	Univariate Analysis with Patient Activation	
Healthcare utilization		
MD Visits [§]		F (2, 61) = .919
ED Visits [§]		F (2, 61) = 1.156
Characteristics of the Environment	<i>R</i>	ANOVA
Community Size		F (1, 62) = 2.95 [†]
Living Arrangement		F (1, 62) = .276
Biological Function		
FEV ₁ [§]		F (1, 62) = 0.86
Symptoms		
PFSDQ-M: Dyspnea Sub score [§]		F (1, 62) = .207
PFSDQ-M: Fatigue Sub score [§]		F (1, 62) = 6.614 [*]
Functional Status		
PFSDQ-M: Activity sub score [§]		F (1, 62) = .708
General Perception of Health		
Single question from SF-36 [§]		F (1, 62) = 4.273 [*]
Overall Quality of Life		
QLI-P	$r(62) = .422^{**}$	

Note: N = 64. Variables with relationships with patient activation with $p < .25$ were included in the Multiple Linear Regression.

Correlation significance (2-tailed): † $p < .25$ * $p < .05$ ** $p < .01$

§ Denotes transformed (dichotomized) variable values used for analysis

Characteristics of the individual. Evaluation of the variables within this domain revealed six to be significantly related to patient activation, which included: (a) gender, (b) level of education, (c) smoking pack years, (d) time since diagnosis of COPD, (e) Body Mass Index , and (f) positive affect. Calculation of Pearson correlation coefficients revealed patient activation and smoking pack years, $r(62) = .319, p = .010$, and positive affect, $r(62) = .519, p = .001$, were strongly positively correlated. Body Mass Index , $r(62) = -.221, p = .079$, was moderately

inversely related to patient activation, indicating people with lower Body Mass Index ($M = 28.67$, $SD = 6.35$) were more activated than those with higher BMI.

One-way ANOVA showed significant direct relationships between patient activation and gender, $F(1, 62) = 1.55$, $p = .217$, level of education, $F(1, 62) = 3.31$, $p = .074$, and years since diagnosis of COPD, $F(1, 62) = 2.73$, $p = .103$. Women ($M = 67.78$, $SD = 16.23$) in the sample were more activated than men ($M = 62.53$, $SD = 16.81$). College education ($M = 70.06$, $SD = 16.17$) was directly related to higher activation, as was longer time since diagnosis of COPD ($M = 67.35$, $SD = 16.81$).

Characteristics of the environment. One characteristic of the environment was significantly associated with patient activation. Community size, specifically urban communities greater than 50,000 people was positively, significantly ($p < .05$) related to patient activation, $F(1, 62) = 2.95$, $p = .091$. This indicated that where people with COPD reside influences their activation. The direction of the relationship showed that people living in urban communities ($M = 69.11$, $SD = 17.30$) were more activated than those living in rural communities ($M = 62.13$, $SD = 15.11$).

Symptoms. The relationship between symptom burden and patient activation was explored through one-way ANOVA calculations using the dichotomized dyspnea and fatigue sub scores from the PFSDQ-M. Only fatigue, $F(1, 62) = 6.61$, $p = .013$, was significantly related to patient activation. Mild fatigue ($M = 68.55$, $SD = 16.19$) was associated with greater patient activation among the adults in the sample than was moderate to severe fatigue ($M = 56.53$, $SD = 14.58$).

General perception of health. Dichotomized responses to the single question from the Medical Outcomes Study SF-36 assessing general perception of health and patient activation

were also examined for association with one-way ANOVA. A modest direct relationship between *very good* or *good* ($M = 69.18, SD = 15.36$) perceived health, $F(1, 62) = 4.27, p = .043$, and patient activation existed in the sample.

Overall quality of life. The total score of the QLI-P reflected participants' perception of their overall quality of life. Pearson correlation coefficient revealed patient activation and overall quality of life were strongly correlated, $r(62) = .422, p < .001$ within the sample.

Specific Aim #3

The final aim of the study was to identify the independent predictors of patient activation in the sample. Stepwise linear regression was calculated to predict the percentage of variance that the candidate patient characteristics and health outcomes explained in patient activation among the sample of adults living with COPD. Independent variables whose univariate test had a significant association with patient activation at a liberal alpha of 0.25 were included in the multivariate regression analysis. These variables are referred to as candidate variables from this point forward. Ten candidate variables entered the stepwise linear regression with patient activation. These included gender, Body Mass Index, education level, smoking pack years, years since diagnosis of COPD, positive affect sub score, community size, fatigue sub score, general perception of health, and overall quality of life.

Together, a statistically significant model containing four independent predictors accounted for 45.4% of the variance in patient activation among adults with COPD. See Table. 12. Positive affect, $\beta = .457, t(4.60) p = .001$ contributed most to the explanation of variance in patient activation, followed by smoking pack years, $\beta = .345, t(3.693), p = .001$ and overall quality of life, $\beta = .264, t(2.670), p = .010$. The fourth independent variable to enter the model

was gender. Female gender was significantly correlated with patient activation, $\beta = -.192$, $t (-2.053)$, $p = .044$.

Table 12. Multiple Linear Regression with Predictor Variables

Independent Variables	<i>B</i>	SE	β	<i>t</i>	<i>p</i>
Positive affect	.852	.185	.457	4.600	.001
Pack years	.260	.070	.345	3.693	.001
Quality of life	.972	.364	.264	2.670	.010
Gender	-6.443	3.138	-.192	-2.053	.044

Note: N = 64

Constant = 0, $p = .123$

$R^2 = .488$, Adjusted $R^2 = .454$, $F(4, 59) = 14.079$, $p < .001$

Multivariate assumptions. No multicollinearity was identified among the predictors and patient activation based on the tolerance values [.88 - 1.00] and variable inflation factors [1.00 – 1.13]. The highest reported correlation index was 15.80, associated with gender entering the model. This finding suggests that some collinearity may exist between gender and at least one other predictor variable. Based on consideration of all three factors, it was determined that multicollinearity was not a concern in the analysis.

Assumptions of normality in the regression were evidenced by a normally distributed histogram of the regression standardized residuals and linear relationship between the observed and expected probabilities of the residuals. Viewing the standardized residuals and predicted values on a scatterplot assessed Homoscedasticity. The plotted residuals did not completely mirror each other above and below the line, but were equally distributed above and below the line. While the scatterplot did not indicate that the assumption of homoscedasticity was completely violated, the appearance suggested that the variance noted in patient activation may have been influenced by an interaction effect between one or more of the predictor variables. An

interaction variable was created and the stepwise linear regression was calculated again. No visual difference in the scatterplot was noted when including the interaction variable in the analysis. It was concluded that normal distribution and linear relationship of the residuals satisfactorily affirm the assumption of normality was met for the analysis.

Calculating Mahalanobis distance and Cook's distance during the regression assessed multivariate outliers. The highest Mahalanobis distance of 8.6916 was significantly less than the χ^2 critical value of 18.467. Cook's distance values were all less than one, confirming the absence of multivariate outliers impacting the regression.

Post hoc power analysis. Initial power analysis using G*Power 3 software (Faul et al., 2009) for multiple linear regression indicated that 98 participants would be needed, assuming an anticipated conservative medium effect size of $f^2 = 0.15$, based on the work of Korpershoek et al. (2016). A post hoc power analysis was conducted after the regression analysis. The actual sample size of 64 participants, four independent predictor variables, alpha of $p < .05$, and calculated effect size of $f^2 = .95$ (based on R^2 of .488) were entered into the statistical power analysis. The post hoc analysis revealed the statistical power for the study was .99 for the overall regression in prediction of patient activation in the sample. Substantial power and the large effect size to detect the strength of the relationship between the predictor variables and patient activation affirm the validity of the regression results despite the small sample size analyzed.

Summary

This dissertation study proposed to describe and examine the relationships among patient characteristics and health outcome factors, as conceptualized in the Revised Wilson Cleary Model (Ferrans et al., 2005), as determinants of patient activation in adults with COPD. Apart from a single study in the Netherlands, little is known about how patient activation is

influenced among adults experiencing the complex, multidimensional health affects of COPD. The results of this dissertation study indicate that several patient characteristics (gender, level of education, time since COPD diagnosis, smoking pack years, Body Mass Index, positive affect, community size) and health outcomes (low fatigue, general perception of health, quality of life) were significantly associated with patient activation. In multivariate analysis, positive affect, smoking pack years, overall quality of life, and female gender independently predicted 45% of the variation in patient activation.

CHAPTER V

DISCUSSION

This chapter presents a summary of the study and important conclusions drawn from the data analyses presented in Chapter IV. The results are organized by each specific aim and related to the current body of research literature. In addition, this chapter provides a discussion of the implications for nursing clinical practice, theory development, and recommendations for future research.

Study Overview

Skills, confidence, and knowledge underpin the capacity of individuals with chronic disease to self-manage (Hibbard et al., 2015). These characteristics and a sense of responsibility for one's own health comprise the concept of patient activation (Hibbard et al., 2004). Patient activation has been shown to be a precursor to successful self-management and predictor of health outcomes in chronic disease (Green et al., 2015). The concept of patient activation has relevance in the treatment of COPD, a progressive incurable lung disease, where the onus of treatment success lies in the capacity of the patient to engage in self-management intensive treatment plans.

Problem and Purpose

There are two key problems noted in the COPD and patient activation research literature. First, the COPD research community has called for further inquiry to identify and understand the patient characteristics *necessary* for effective self-management. These

characteristics may hold the key to understanding why less than one-half of all people with COPD engage in recommended self-management. The current evidence is not only insufficient; it is clouded by conflicting results of self-management intervention studies of the past decade. Second, despite the emerging body of evidence suggesting patient activation is a critical construct in chronic disease care (Coventry et al., 2014; Green, et al., 2015), determinants and mediators of the concept are still relatively unknown (Hibbard, et al., 2015). Additionally, little is known about how the complex, systemic nature of COPD affects patient activation development (Evans & Morgan, 2014; Korpershoek, et al., 2016).

The purpose of this study was to describe and examine the relationships among patient characteristics and health outcome factors as determinants of patient activation level in adults with COPD. To guide this cross-sectional, descriptive correlational study, the Revised Wilson Cleary Model (Ferrans et al., 2005) was adapted by adding the concept of patient activation to the model. Patient activation was integrated as an additional outcome concept with overall quality of life as they share similar integrated biopsychosocial complexity (Hibbard & Mahoney, 2010). The model organized a continuum of complex and integrated health outcomes and patient characteristics integral to the experience of COPD for study (Guyatt, et al., 2007). The specific aims to be addressed by the study were to: (a) describe the patient characteristics (individual and environmental), health outcome factors (biological function, symptoms, functional status, general perception of health, and overall quality of life), and patient activation experienced by a cross-sectional sample of adults in the United States with COPD; (b) examine the unadjusted associations that patient characteristics and health outcome factors have with patient activation in the sample; and (c) identify the independent predictors of patient activation in the sample.

A random sample of adults who received care for COPD at the study site were invited to participate in a postal survey study. Data were collected from 64 participants through completion of a questionnaire comprised of validated tools aligned with each of the domains of the conceptual framework guiding the study. In addition, spirometry data were abstracted from participants' medical records. The presence, strength, and directionality of relationships between the patient characteristics, health outcomes and patient activation were examined through univariate correlation analyses. The patient characteristics and health outcomes significantly associated with patient activation were then entered into stepwise linear regression models to identify the variables that explained the greatest variance in patient activation.

Major Findings

Participants in this study were mostly older men and women in their 70s. Few respondents lived alone as most were married or living with a significant other. The majority had been diagnosed with COPD for several years; their most recent spirometry revealed moderate to severe airway obstruction. They had significant smoking pack years and were overweight. Socioeconomically, the sample was educated, living in urban communities, and had incomes greater than \$50,000 per year. The sample's demographics were consistent with the known demographics of the COPD population in the United States (CDC, 2017; Croft et al., 2018). Despite having significant obstructive lung disease, the participants had few physician visits and emergency room visits in the past year. Except for one person, all participants experienced symptoms of fatigue and dyspnea, and noted a change in their current functional status as compared to before being diagnosed with COPD. The degree of impact of the symptoms and change in function was mild for most of the sample. Notably, the degree of positive affect, or an optimistic outlook on life, and perception of good quality of life was high among the sample.

This study found statistically significant associations between individual and environmental characteristics, specifically gender, Body Mass Index, educational level, smoking pack years, time since COPD diagnosis, community size, and patient activation. Additionally, the health outcomes of fatigue, general perception of health, and overall quality of life were positively related to patient activation in the sample. Multivariate regression analysis revealed four determinants, positive affect, smoking pack years, overall quality of life, and gender, which together explained 45.4% of the variance in patient activation. The next section will discuss the major findings related to patient activation and the new knowledge emerging from this study.

Major Findings Related to Patient Activation

Patient activation is an important factor when planning care with patients diagnosed with COPD. The goals of COPD treatment plans are to limit physical and lung functional decline and maintain quality of life (Qaseem et al., 2011). Diligent self-management by patients is required to achieve these goals. People with higher patient activation are more likely to participate in recommended activities associated with collaborative self-management treatment plans for COPD (Dixon, Hibbard & Tusler, 2009).

The mean Patient Activation Measure-13 (PAM) score of the sample was 66 ($SD = 16$) (maximum score 100), which lies near the cut-off point between PAM Level 3 and 4. According to Hibbard et al., (2005), this score indicates that the majority of participants in the sample were activated and would be able to begin taking action toward self-management by initiating new health behaviors. Forty-eight percent of the sample participants ($n = 31$) were highly activated at PAM Level 4. At this level, it would be expected that these individuals were engaged in their self-management and with their providers. In times of stress (e.g., COPD exacerbation) they may need additional support to incorporate new behaviors or get back on track with established self-

management routines (Hibbard et al., 2005). Fourteen percent of the sample were in Level 2 activation, associated with early awareness of the need to do more for their health, yet having little knowledge and sense of efficacy to make any changes on their own (Hibbard et al., 2004). The remainder of the sample was in the lowest level of activation, Level 1. This group would have a passive perspective toward taking responsibility to manage their health because of limited knowledge about their condition and believing their doctor should be in charge of their health (Hibbard et al., 2004).

The patient activation scores found in this study sample were higher than those reported by Halding and Grov (2017) and Korpershoek et al. (2016) in their examinations of Dutch adults with COPD. While Halding and Grov examined community dwelling adults' activation levels, Korpershoek et al. (2016) included patients living in skilled nursing facilities and community-dwelling adults with COPD in their examination patient activation determinants. Korpershoek et al. (2016) did not report if there were differences in PAM scores between the community-dwelling participants and those in skilled care settings. Clinically, there should be a distinction in patient activation scores among people who live in skilled care facilities and are not autonomous in managing their health. As evidenced by the high capacity to self-manage (PAM Levels 3 and 4) and health outcomes reported, the findings suggest that most of the sample were self-managing their COPD.

Significant Relationships Among Variables and Patient Activation

Univariate statistical analyses were conducted to explore the presence, strength, and direction of relationships between the variables described in each of the domains of the Revised Wilson Cleary Model (Ferrans et al., 2005) and patient activation. The characteristics of people

living with COPD significantly associated with their patient activation level provide a picture of activation in this population that are not yet described in the literature.

Consistent with other studies of determinants of patient activation, this study found lower BMI was associated with higher patient activation (Korpershoek et al., 2016; Liu et al., 2014). The majority of the participants in this sample were overweight or obese ($M = 28.67$, $SD = 6.35$), (WHO, 2018). Ding et al., 2017 noted that being overweight with COPD is prevalent in the world. They found that 74% of the people with COPD in U.S. studied were overweight or obese, compared to 60% in the European countries studied. Their study corroborates the subtle differences noted in overweight BMI of this U.S. sample and that of Korpershoek et al., (2016) in the Netherlands. How BMI influences activation levels has not been discussed in the literature and warrants further study.

Lower symptom burden, specifically fatigue, was related to activation in the sample. The fact that fatigue, not dyspnea, was associated with patient activation was an interesting finding. Though fatigue is known to be prevalent in COPD, dyspnea is the predominant symptom assessed clinical research. Controlling fatigue and dyspnea are self-management behaviors considered most worthwhile by those with COPD (Chen et al., 2008) and together significantly contribute to decreased quality of life (Guyatt et al., 2007). The processes by which fatigue and activation were associated in this sample deserve further investigation.

Sociodemographic factors, higher levels of formal education and larger community sizes were strongly associated with higher patient activation scores in analysis. These findings were consistent with the Dutch sample of people living with COPD examined by Korpershoek, et al., (2016). Acquiring and applying the necessary skills, knowledge, and confidence to self-manage is the hallmark of patient activation (Hibbard et al., 2004). Dunlay et al. (2017) and

others have posited that a higher level of formal education improves health literacy, positively impacting patient activation levels over time (Green et al., 2015; Hibbard et al., 2007, 2015; Marshall et al., 2013). Formal education develops problem solving ability and cognitive skills to distill and apply knowledge (Heide et al., 2013). Further, education develops “soft skills” of control, autonomy, and personal efficacy (Zimmerman et al., 2013). These skills underpin the construct of patient activation. (Hibbard et al, 2004; Hibbard & Mahoney, 2010). In addition, living in an urban community has been proposed to support higher activation of people with chronic disease by having greater access to health care and less social isolation (Chen et al., 2014). Similarly, other authors have posited limited health care resources and isolation in rural communities as contributing to lower patient activation among older adults with COPD living there (Croft et al., 2018).

People who had lived with the disease longer (four or more years) were more activated in the sample of this study. There was a moderately significant association between the years since diagnosis with COPD and patient activation. This finding is supported by Hibbard and Mahoney’s (2010) assertion that the length of time people live with a chronic condition is positively related to their activation. The authors rationalized that the more experience people have managing the good and bad days common in chronic disease, the greater they develop efficacy and knowledge, which fosters activation for self-management. This result is contrary to the findings of Korpershoek et al., (2016) which showed lower patient activation was associated with greater number of years living with the diagnosis of COPD. The results of this analysis warrant further study to better understand the high levels of activation in later years of COPD.

Congruent with the conceptual model used in this study, integrated physiological and psychosocial factors influenced how people living with COPD perceived and rated their health

(Bentsen et al., 2008). Among the sample, a significant relationship favoring *very good* or *good* ($M = 69.18$, $SD = 15.36$) perceived health and patient activation was found. This is corollary to findings in other chronic disease studies of poor perception of health positively associated with lower patient activation scores (Chubak et al., 2010; Hibbard et al., 2015). Self-rated health has been found to independently predict COPD-related mortality across diverse epidemiological samples (Benzo et al., 2010; Nguyen et al., 2008; Park and Larson, 2016; Wagner & Short, 2014), thus it has become an integral factor in patient assessment.

Determinants

Among the people in the sample, their high positive affect and perception of overall quality of life, combined with the life experiences of gender and smoking, explained almost 45% of the variance in their patient activation. How each of the independent predictors contributed to the model provides further insight to the unique impact of COPD on activation. Positive affect and perception of quality of life were strongly correlated with patient activation and contributed to the regression model. The mechanisms of smoking pack years and gender on the development of patient activation are less clear. Each of the determinants and their relationship with patient activation in the context of the COPD population are discussed below.

Positive affect. “Emotions are key underpinnings of activation” (Hibbard & Mahoney, 2010, p. 378). In development of the Patient Activation Measure, Hibbard et al. (2004) asserted that positive affect contributed significantly to developing an individual’s self concept as a self-manager, the outward expression of their activation level. Positive affect was strongly positively correlated with patient activation in the sample. This is the first time positive affect has been identified as a predictor of activation level in the literature. The mean positive affect sub score of the PANAS was 32 ($SD = 8.9$) (maximum PANAS sub score = 50), suggesting participants had a

moderate level of dispositional positive affect. This means that they generally had a positive outlook on life and feelings of optimism (Watson et al., 1988). The mean negative affect sub score was low at 16 ($SD = 5.9$), indicating participants in the sample generally did not have negative dispositions and pessimistic views on life. Considering most of the sample had lived with COPD for many years, well-established positive emotions and an optimistic outlook on life may have contributed to their activation development.

The role of positive emotions is relevant to the trajectory of COPD where in progression of symptoms, debility, and acute exacerbations require emotional resources to adapt and problem solve (Bentsen et al., 2008). In the context of collaborative self-management of COPD, positive affect has been associated with better health management and engagement with the healthcare team (Benzo et al., 2016). Further, the ratio of positive to negative affect, or positivity ratio, of people living with COPD has been shown to mediate the relationship between patient's investment in self-management behavior and better overall quality of life (Benzo et al., 2016). Identifying positive affect as a strong predictor of self-management capacity in COPD provides a target for nursing interventions to improve self-management and activation levels of patients with COPD.

Overall quality of life. In this study, univariate analysis revealed patient activation and overall quality of life were strongly correlated. Therefore, adults in the sample who perceived their quality of life as better were more activated. This finding is congruent with studies of other chronic disease populations (Dixon et al., 2009; Goodworth et al., 2016; Hibbard et al., 2007, 2015; Mosen et al., 2007). More importantly, this study found a predictive relationship between quality of life and patient activation, $\beta = .264$, $t(2.670)$, $p = .010$, which for the first time integrates a direct association between patient activation and overall quality of life in the self-

management capacity of people living with COPD. Examination of any measure of quality of life was notably absent in Korpershoek et al.'s (2016) study of determinants of patient activation in COPD. This is an important finding linking the COPD and patient activation literature related to self-management and subsequent health outcomes. The perception of one's quality of life is a powerful predictor of COPD-related health behaviors, co-morbidity, mortality, and health care utilization (Case et al., 2017; Guyatt et al., 2007). Patient activation also predicts, mediates, and directly influences self-management engagement and health outcomes in chronic disease (Green et al., 2015; Hibbard et al., 2015).

Improving quality of life through collaborative self-management and medical intervention is a priority in COPD care (Qaseem et al., 2011). Though the literature has suggested activation level and quality of life may be related through the process of self-management in chronic disease (Dixon et al., 2009), the relationship between quality of life and patient activation has not been previously studied with sufficient rigor in the COPD population. It is unclear if better perceived quality of life supports or maintains patient activation, or if higher activation and subsequent health outcomes lead to improved quality of life (Goodworth et al., 2016). This important link between quality of life and patient activation must be investigated further to understand how the relationship can be translated practically to the care of patients with COPD.

Smoking pack years. More than 75% of all COPD diagnoses are attributed to smoking (CDC, 2017). When diagnosed with COPD, many people express guilt that their conscious use of cigarettes led to their diseases. The quantity of cigarettes or cigars smoked over time by (participants in this study averaged 47 pack years. This would suggest that most participants smoked at least a pack of cigarettes a day for approximately 40 years. The average pack years of

the sample are indicative of the national norm of a pack-to-two-pack per day smoker of the late 1950s and 1960s (Gardner, 2011), when most of the samples were likely introduced to smoking.

The direct, predictive relationship found between smoking pack years, $\beta = .345$, t (3.693), $p = .001$, and patient activation is an interesting finding. First, the correlation between the two variables indicates that people in the sample who were heavier smokers, as quantified by their pack years, were more activated than people who smoked less. Second, higher pack years strongly contributed to the model explaining the variance in patient activation among the sample. No other studies identified through literature review examined the association between smoking pack years and patient activation. Other studies of patient activation determinants examined smoking *habits* (active or former) but not quantity of tobacco smoked. Korpershoek et al. (2016) found smoking habits were associated with patient activation level in people with COPD. However, the variable did not explain variance in patient activation in their regression analysis. Studies of patient activation determinants in other chronic disease populations did not find any relationship between smoking habits with patient activation (Dunlay et al., 2017; Schmaderer et al., 2016).

While the mechanisms are unclear why smoking pack years contributed significantly to the model, the result cannot be ignored. To explore reasons for this result, consideration of the theoretical underpinnings of patient activation and nature of cigarette smoking must be considered. It can be posited that a unique sense of personal responsibility exists among people with COPD. Many people express significant guilt regarding their smoking habits when diagnosed with COPD (Celli et al., 2015). As most COPD is attributed directly to cigarette smoking, patients who are current or former smokers seem to accept a degree of responsibility for what has happened to their health related to their smoking habits. The quantity of cigarettes

smoked is influenced by social norms, finances, and perceived effect from smoking (Benowitz, 2010). These factors contribute to many with COPD having high smoking pack years. To smoke tobacco in an environment of social pressures and strong recommendations from healthcare providers requires people to make conscious decisions and problem solve to maintain this behavior, even if it is a risk to their health and socially undesirable. Responsibility and confidence in making decisions about one's health underpin activation (Hibbard et al., 2004).

Capability and confidence also underpin activation (Hibbard et al., 2004). The addictive properties of nicotine in tobacco promote the long-term habituation to cigarette smoking (Benowitz, 2010). Quitting smoking is a significant self-management success, one that builds efficacy and can be leveraged toward other self-management behaviors in the setting of COPD. Efficacy is central to capability and confidence to make behavioral changes to support self-management (Hibbard & Mahoney, 2010). Participants with greater pack years who had successfully quit smoking may see achieving this goal as a pivotal success in their health. Clearly, the role of smoking within this sample of adults with COPD who were highly activated warrants further study to explicate and understand these factors.

Gender. Gender has had inconsistent associations with patient activation and several elements of care in COPD in the literature. In this study, even though gender was only modestly associated with patient activation in univariate analysis, it did contribute to the overall regression model explaining variance in patient activation score. Specifically, males were less activated than females in all analyses. Other researchers have warned that associations between gender and patient activation should be considered cautiously in samples with unequal gender distribution (Green et al., 2015; Hibbard et al., 2015). Women outnumbered men by 20% in this sample. Several studies that identified a positive relationship between female gender and patient

activation have also had disproportionately large numbers of women in the samples (Fowles et al., 2009; Goodworth et al., 2016; Hibbard et al., 2005, 2015, 2016). However, none of the studies published to date have identified gender as an independent predictor of patient activation. This is a unique finding of this study.

The process underlying greater activation among women in the sample is not entirely clear. How women's experiences in chronic disease, as opposed to men's, impact activation has not been explored in the literature. Similarly, the differences between men and women in terms of their experiences with COPD have only recently begun to be examined and reported in the literature. Awareness of the differences between women and men in relation to COPD only emerged when the numbers of newly diagnosed and mortality rates began to favor women in the early 2000s (ALA, 2017; Celli et al., 2015; Pruitt, 2014). Evidence has shown that smoking habits, environmental exposures, genetic predisposition, symptoms and even response to treatments vary between the sexes (Jenkins et al., 2017). Women are more likely to be diagnosed later in the disease trajectory when symptoms and obstruction are greater (Jenkins et al., 2017). However, once diagnosed women have more healthcare encounters and interactions with providers than men (Jenkins et al., 2017). The timing of diagnosis, life experiences, and exposure to providers may contribute to the skills and knowledge that predicate activation (Hibbard et al., 2007). The relationship between gender, patient activation level, and self-management requires further study to understand how these factors may influence outcomes for women with COPD.

Summary and Implications

This descriptive correlational study expands the limited scientific knowledge of determinants of patient activation of adults living with COPD in the United States. Cognitive-behavioral influences appear to be at the heart of self-management capacity for those with COPD

(Kaptein et al., 2014; Korpershoek et al., 2016). The results provide: (a) insight to the characteristics and health outcomes experienced by a sample of people living with COPD in this country, (b) knowledge of significant relationships and determinants among these factors and patient activation, and (c) objective targets for future COPD self-management research. Further, the results from this study address a gap in the evidence base related to the patient factors necessary to engage in self-management of COPD. Based on the findings, implications for nursing clinical practice, theory advancement, and future research are presented.

The multidimensional Revised Wilson Cleary Model of Health-related Quality of Life (Ferrans et al., 2005) was used to organize and examine phenomena unique to people living with COPD as they related to patient activation. The model builds from the singular, objective biological factors to the highly integrated, complex overall quality of life (Wilson & Cleary, 1995). Patient activation was integrated as an end-point in the model as it shares similar biopsychosocial complexity with overall quality of life (Hibbard & Mahoney, 2010). Unidirectional relationships between variables in each model domain, except biological function and functional status, were revealed across the continuum of increasing complexity with patient activation. Though the model was not tested for fit and reciprocal relationships among the domains were not explored in this study, the domains and proposed relationships among them contributed to the results of this study. The characteristics of the individual, explicated by Ferrans et al. in 2005, provided most of the variables significantly associated with activation level of people living with COPD. Adaptation to include patient activation as an end-point in the model was supported by the strong correlation found between overall quality of life and patient activation in the sample. Guyatt, Ferrans, and colleagues (2005) suggested that in the setting of COPD, all domains of the Wilson and Cleary Model (Wilson & Cleary, 1995) integrate to

influence the individual's perception of overall quality of life. Further study of the relationships between and among the domains of the model may reveal integration of the domains and patient activation not identified in this study.

Implications for Nursing Clinical Practice

Findings from this study will inform nurses who care for patients with COPD what patient activation is, how it is related to self-management outcomes, and what patient characteristics influence it. The independent predictors of patient activation provide new targets for self-management interventions to improve engagement and support activation development in people with COPD. In addition, this study identified several characteristics and health outcomes of people living with this condition significantly associated with their patient activation level. Nurses are in a pivotal position to apply knowledge of activation predictors toward identification of self-management capacity of patients and engage them in appropriate behavioral interventions and care coordination services (Hibbard & Greene, 2013; Naylor et al., 2013).

- Patient activation is an important characteristic to assess and explore with patients as to its potential to be modified and contribute to self-management engagement and health outcomes. Use of the Patient Activation Measure (Hibbard et al., 2005) in the clinical setting could contribute to improved care in this population.
- Using the PAM to assess and evaluate patients participating in self-management, care coordination, and pulmonary rehabilitation programs would provide objective measure of self-management capacity to tailor the care plan and meaningfully evaluate outcomes. Further, PAM scores can indicate how intensely to follow high-risk patients in care transitions and to determine priorities in their care plan (Hibbard et al., 2016).

- Measurement of the patient activation score can augment clinical risk prediction for emergency department visits and hospitalization rates, directly associated with all-cause mortality in the COPD population (Dhamane et al., 2015; Hibbard et al., 2016). Patients with PAM Level 3 and 4 are significantly less likely to have a costly emergency room visit and subsequent hospitalization as compared to those at Level 1 (Hibbard et al., 2016).
- The importance of thorough psychosocial assessment of people with COPD prior to planning interventions and supportive care for self-management cannot be understated. Mood, affect, self-rated health, and perception of quality of lives are strongly associated with activation level and self-management capacity of patients.
- Positive affect and overall quality of life present modifiable targets for strengths-based nursing interventions to improve self-management engagement and health outcomes among people living with COPD (Gottlieb and Gottlieb, 2017).
- Quantification of pack years should be included in assessment of smoking status of people with COPD. Smoking history may reflect a hidden strength among people with COPD that contributes to their activation level, and thus, capacity to self-manage.

Implications for Nursing Theory Advancement

The Revised Wilson Cleary Model of Health-related Quality of Life (Ferrans et al., 2005) provided an adaptable, comprehensive frame to examine the unique patient characteristics and health outcomes of people living with COPD and their relationships with patient activation. It is recommended that the associations between and *among* the domains of the model and patient activation are examined with larger sample sizes to fully explicate the relationships found in this study and identify if others exist in the COPD population. Further, structural equation

modeling is recommended to test the fit of the model for future exploration of causal relationships and prediction of patient activation precursors. Advancement of this theory could potentially identify mechanisms of patient activation development that underlie self-management efficacy across chronic disease states. Use of the model to organize and describe the findings of this study demonstrated the utility of the model to advance the understanding of patient activation in COPD, filling a gap in the literature.

Recommendations for Future Research

This was the first study of its kind to describe patient characteristics and health outcomes associated with patient activation in people living with COPD in the U.S. In addition, this study contributed four unique determinants of patient activation, expanding knowledge of this concept within the minimally studied COPD population. However, this study does not exist in isolation. Further study is needed with more diverse samples to fully explicate the significant associations, predictors, and relationships among them and patient activation. Mixed-methods approaches are needed to explore the lived experience of adults with COPD at various levels of patient activation. This would provide rich knowledge missing from the current literature, and perhaps reveal other factors relevant to lend additional support for the predictors explicated in this study.

Adoption of the Patient Activation Measure (Hibbard et al., 2004) as a core outcome measure in COPD self-management studies is needed. Not only can the PAM provide a sensitive evaluation measure of intervention efficacy, it can be used to tailor self-management interventions to move patients developmentally to their optimal level of activation. Use of the PAM would address the heterogeneity prevalent in COPD self-management outcomes and contribute as a common data element for data sharing across nursing studies, consistent with the

recommendations of the National Institute of Nursing Research (Grady & Daley, 2014; Moore et al., 2016).

Recruitment of patients in exploratory and behavioral COPD research is challenging (Benzo et al., 2017). Though response rate was low for this survey, it was encouraging to see so many people with severe and very severe (end stage) COPD agree to participate. Few young and less affected (mild COPD) people identified participated, consistent with other COPD studies that identified those less affected did not believe they were sick enough or were not sure they “had COPD” (Benzo et al., 2015). To capture the entire range of COPD severity and experiences in this population, strategies to optimize survey design and return rate for optimal sample size and diversity must be explored.

Additional questions should be asked of participants to gain deeper understanding of the results of this study. First, questions to assess the relationship between current and former smoking practices in the context of pack years are needed to explain the strong association between smoking pack years and patient activation. Second, as patient activation is modifiable and developmental, asking participants about prior pulmonary rehabilitation or participation in collaborative self-management programs (i.e., nurse-led educational programming in comprehensive pulmonary care center) is recommended. This information would shed light on exposure to behavioral interventions that may have increased the patient activation level of the sample.

Conclusion

Patient activation is an important construct that can contribute to the advancement of COPD self-management science and nursing care. COPD multidimensionality affects the individual and their ability to self-manage the condition. The relationship between self-

management engagement and positive health outcomes associated with greater activation are important in the setting of COPD. This study revealed several mechanisms of complex health behaviors that underlie self-management capacity in COPD. Thorough nursing assessment of patient characteristics, including outlook on life, social history (smoking), gender, and satisfaction with their quality of their life will provide meaningful insight to the capacity of an individual with COPD to self-manage their disease. Use of the Patient Activation Measure (Hibbard et al., 2004, 2005) in clinical settings and self-management research would positively contribute to the care of this vulnerable population. Further research is needed to explicate the modifiable and non-modifiable factors that influence patient activation in the COPD population.

APPENDICES

Appendix A
Positive and Negative Affect Scale (PANAS)

This scale consists of several words that describe different feelings and emotions. Read each word and then **circle** the choice that best describes to what extent you are feeling this way **in the past month**. Remember, there are no right or wrong answers, so please give us your honest opinion.

		Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
1.	Interested.....	1	2	3	4	5
2.	Distressed.....	1	2	3	4	5
3.	Excited.....	1	2	3	4	5
4.	Upset.....	1	2	3	4	5
5.	Strong.....	1	2	3	4	5
6.	Guilty.....	1	2	3	4	5
7.	Scared.....	1	2	3	4	5
8.	Hostile.....	1	2	3	4	5
9.	Enthusiastic.....	1	2	3	4	5
10.	Proud.....	1	2	3	4	5
11.	Irritable.....	1	2	3	4	5
12.	Alert.....	1	2	3	4	5
13.	Ashamed.....	1	2	3	4	5
14.	Inspired.....	1	2	3	4	5
15.	Nervous.....	1	2	3	4	5
16.	Determined.....	1	2	3	4	5
17.	Attentive.....	1	2	3	4	5
18.	Jittery.....	1	2	3	4	5
19.	Active.....	1	2	3	4	5
20.	Afraid.....	1	2	3	4	5

Watson, D., Clark, L. & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personality and Social Psychology*, 54(6), 1063-1070.

Appendix B
Pulmonary Functional Status and Dyspnea Questionnaire-Modified (PFSDQ-M)

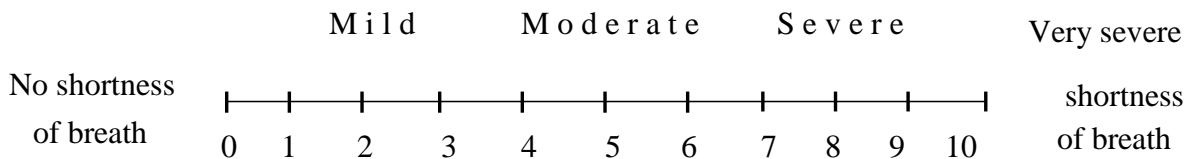
DEGREE OF SHORTNESS OF BREATH ASSESSMENT

INSTRUCTIONS: The following questions relate to your **discomfort in breathing**. Please check the most accurate answer.

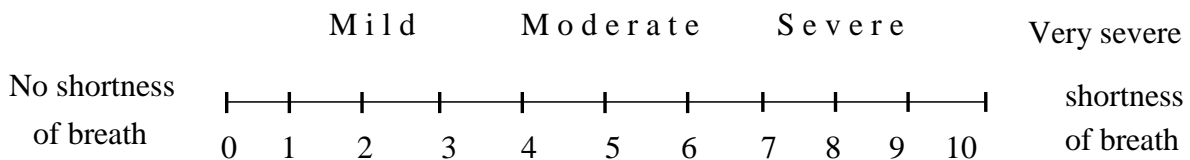
1. Do you ever experience shortness of breath? Yes_____ No_____
2. How many times a month do you experience severe to very severe shortness of breath?

Using the following scale, place a mark on the line between 0 (no shortness of breath) to 10 (very severe shortness of breath) in response to the following questions.

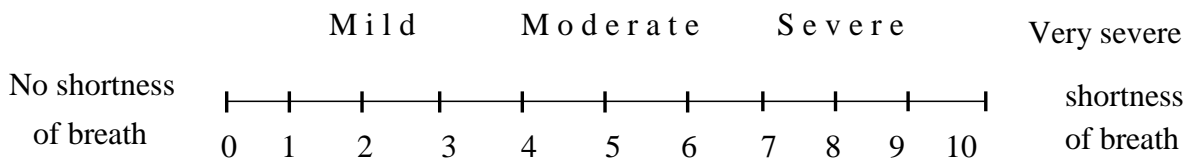
3. Indicate how you've felt on **most days** during the past year.



4. Indicate how you feel **today**.



5. Indicate how you feel with most **day-to-day** activities.



DEGREE OF SHORTNESS OF BREATH ASSESSMENT

Lareau, S. C., Breslin, E. H., & Meek, P. M. (1996). Functional status instruments: outcome measure in the evaluation of patients with chronic obstructive pulmonary disease. *Heart & Lung: The Journal of Acute and Critical Care*, 25(3), 212-224.

INSTRUCTIONS: Rate the following activities on a scale of 0 to 10 according to the degree of **shortness of breath** each activity generally causes you.

Complete the form as follows: Place an “X” in the column under “0” if the activity generally causes you no shortness of breath. **Leave blank** those activities you do not typically perform in a normal week.

ACTIVITY	None	Mild			Moderate			Severe			Very Severe
	0	1	2	3	4	5	6	7	8	9	10
1. Brushing/combing hair											
2. Putting on shirt											
3. Washing hair											
4. Showering											
5. Raising arms overhead											
6. Preparing a snack											
7. Walking ten feet (3½ meters)											
8. Walking on inclines											
9. Walking on bumpy terrain											
10. Climbing 3 stairs											

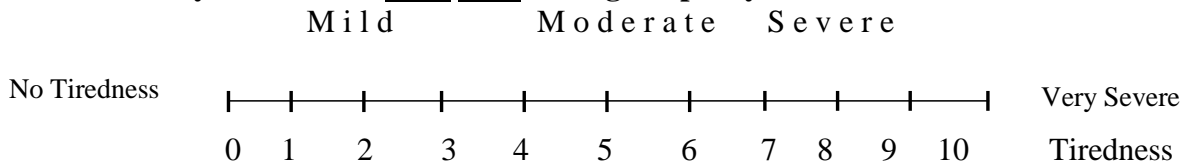
DEGREE OF TIREDNESS ASSESSMENT

INSTRUCTIONS: The following questions relate to how **tired or worn out you feel**. Please check the most accurate answer.

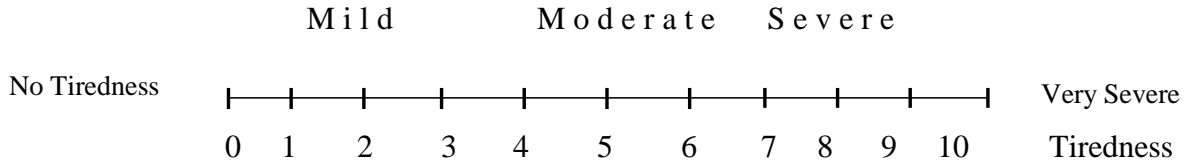
1. Do you ever experience tiredness/feeling worn out? Yes__ No_____
2. How many times a month do you experience severe to very severe tiredness? _____

Using the following scale, place a mark on the line between 0 (no tiredness) to 10 (very severe tiredness) in response to the following questions.

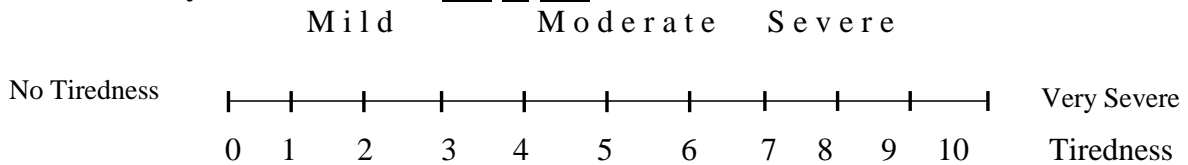
3. Indicate how you've felt on most days during the past year.



4. Indicate how you feel today.



5. Indicate how you feel with most day-to-day activities.



ACTIVITY	None	Mild			Moderate			Severe			Very Severe
	0	1	2	3	4	5	6	7	8	9	10
1. Brushing/combing hair											
2. Putting on shirt											
3. Washing hair											
4. Showering											
5. Raising arms overhead											
6. Preparing a snack											
7. Walking ten feet (3½ meters)											
8. Walking on inclines											
9. Walking on bumpy terrain											
10. Climbing 3 stairs											

ACTIVITY ASSESSMENT

INSTRUCTIONS: The following is a list of activities commonly performed by adults. For each activity listed, please place an **X** in the appropriate box, indicating your involvement with the activity now as compared to before you developed breathing problems. Please respond to every activity listed.

Complete the form as follows:

1. **"Has never been an Activity"**: Check this box near each activity in which you have never participated.
2. Columns numbered 0 through 10 represent a range of activities from **"As Active As I've Ever Been"** to **"Have Omitted Entirely"**. Indicate by placing an **X** in the area which best reflects your current involvement in the activity.

ACTIVITY	Has Never Been An Activity	As Active As Ive Ever Been	Minor Change			Moderate Change			Extreme Change			Have Omitted Entirely
			0	1	2	3	4	5	6	7	8	
1. Brushing/ combing hair		0	1	2	3	4	5	6	7	8	9	10
2. Putting on a shirt												
3. Washing hair												
4. Showering												
5. Raising arms overhead												
6. Preparing a snack												
7. Walking 10 feet (3.5 meters)												
8. Walking on inclines												
9. Walking on bumpy terrain												
10. Climbing 3 stairs												

Appendix C
Quality of Life Index Pulmonary Version-III

Part 1. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH?		Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1.	Your health?	1	2	3	4	5	6
2.	Your health care?	1	2	3	4	5	6
3.	The amount of pain you have?	1	2	3	4	5	6
4.	Your ability to breathe without shortness of breath?	1	2	3	4	5	6
5.	The amount of energy you have for everyday activities?	1	2	3	4	5	6
6.	Your ability to take care of yourself without help?	1	2	3	4	5	6
7.	The amount of control you have in your life?	1	2	3	4	5	6
8.	Your chances of living as long as you would like?	1	2	3	4	5	6
9.	Your family's health?	1	2	3	4	5	6
10.	Your children?	1	2	3	4	5	6
11.	Your family's happiness?	1	2	3	4	5	6
12.	Your sex life?	1	2	3	4	5	6
13.	Your spouse, lover, or partner?	1	2	3	4	5	6
14.	Your friends?	1	2	3	4	5	6
15.	The emotional support you get from your family?	1	2	3	4	5	6

16.	The emotional support you get from people other than your family?	1	2	3	4	5	6
17.	Your ability to take care of family responsibilities?	1	2	3	4	5	6
18.	How useful you are to others?	1	2	3	4	5	6
19.	The amount of worries in your life?	1	2	3	4	5	6
20.	Your neighborhood?	1	2	3	4	5	6
21.	Your home, apartment, or place where you live?	1	2	3	4	5	6
22.	Your job (if employed)?	1	2	3	4	5	6
23.	Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24.	Your education?	1	2	3	4	5	6
25.	How well you can take care of your financial needs?	1	2	3	4	5	6
26.	The things you do for fun?	1	2	3	4	5	6
27.	Your chances for a happy future?	1	2	3	4	5	6
28.	Your peace of mind?	1	2	3	4	5	6
29.	Your faith in a higher power?	1	2	3	4	5	6
30.	Your achievement of personal goals?	1	2	3	4	5	6
31.	Your happiness in general?	1	2	3	4	5	6
32.	Your life in general?	1	2	3	4	5	6
33.	Your personal appearance?	1	2	3	4	5	6
34.	Yourself in general?	1	2	3	4	5	6
35.	Your relief from coughing?	1	2	3	4	5	6
36.	The changes in your life that you have had to make because of your lung condition?	1	2	3	4	5	6

		HOW IMPORTANT TO YOU IS?					
		Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1.	Your health?	1	2	3	4	5	6
2.	Your health care?	1	2	3	4	5	6
3.	Having no pain?	1	2	3	4	5	6
4.	Having no shortness of breath?	1	2	3	4	5	6
5.	Having enough energy for everyday activities?	1	2	3	4	5	6
6.	Taking care of yourself without help?	1	2	3	4	5	6
7.	Having control over your life?	1	2	3	4	5	6
8.	Living as long as you would like?	1	2	3	4	5	6
9.	Your family's health?	1	2	3	4	5	6
10.	Your children?	1	2	3	4	5	6
11.	Your family's happiness?	1	2	3	4	5	6
12.	Your sex life?	1	2	3	4	5	6
13.	Your spouse, lover, or partner?	1	2	3	4	5	6
14.	Your friends?	1	2	3	4	5	6
15.	The emotional support you get from your family?	1	2	3	4	5	6
16.	The emotional support you get from people other than your family?	1	2	3	4	5	6
17.	Taking care of family responsibilities?	1	2	3	4	5	6
18.	Being useful to others?	1	2	3	4	5	6

19.	Having no worries?	1	2	3	4	5	6
20.	Your neighborhood?	1	2	3	4	5	6
21.	Your home, apartment, or place where you live?	1	2	3	4	5	6
22.	Your job (if employed)?	1	2	3	4	5	6
23.	Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24.	Your education?	1	2	3	4	5	6
25.	Being able to take care of your financial needs?	1	2	3	4	5	6
26.	Doing things for fun?	1	2	3	4	5	6
27.	Having a happy future?	1	2	3	4	5	6
28.	Peace of mind?	1	2	3	4	5	6
29.	Your faith in a higher power?	1	2	3	4	5	6
30.	Achieving your personal goals?	1	2	3	4	5	6
31.	Your happiness in general?	1	2	3	4	5	6
32.	Your life in general?	1	2	3	4	5	6
33.	Your personal appearance?	1	2	3	4	5	6
34.	You to yourself?	1	2	3	4	5	6
35.	Being free from coughing?	1	2	3	4	5	6
36.	The changes in your life that you have had to make because of your lung condition?	1	2	3	4	5	6

Ferrans, C. E., & Powers, M. J. (1985). Quality of life index: development and psychometric properties. *Advances in Nursing Science*, 8(1), 15-24.

Appendix D
Global Self-rating of Health
(Adapted from Ware & Sherbourne, 1992)

Instructions: Please respond to the question by marking one box in the row.

	Excellent	Very Good	Good	Fair	Poor
In general, would you say your health is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E
Demographic Form

Instructions: Answer questions as they relate to you. For most answers, check the box(es) most applicable to you or fill in the blanks.

About You

1. Your Age in Years, Today

(Select only one.)

- 40-50
- 50-60
- 60-70
- 70-80
- 81 or more

2. Your Gender

(Select only one.)

- Female
- Male
- Transgender

3. Your Ethnicity

(Select only one.)

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown

4. Your Race

(Select only one.)

- American Indian/Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- More than one race

5. Your Marital Status

(Select only one.)

- Married
- Civil Union/Domestic Partnership
- Widowed
- Living with significant other
- Single (never married)
- Divorced/Separated

6. Your Educational Background

(Select only one.)

- Less than high school
- Graduated high school or GED
- Some college or technical school
- Graduated college
- Postgraduate school or degree

7. Your Employment Status

(Select only one.)

- Currently working
- On leave of absence
- Retired (not due to ill health)
- Disabled and/or retired because of ill health
- Homemaker
- Unemployed

8. Your Income Level

(Select only one that reflects all sources of income earned in the past year.)

- Less than \$10,000
- \$10,000 to less than \$20,000
- \$20,000 to less than \$35,000
- \$35,000 to less than \$50,000
- \$50,000 to less than \$75,000
- \$75,000 to less than \$100,000
- \$100,000 or more
- I prefer not to answer this question.

About Your Residence

9. Who do you live with?

(Select only one.)

- I live alone
- I live with family or friends

10. Where do you live?

(Select only one.)

- In a community of < 50,000 people
- In a community of > 50,000 people

About Your Breathing

11. How long have you been diagnosed with COPD (Chronic Obstrcutive Pulmonary Disease, Emphysema, or Chronic Bronchitis)?

(Select only one.)

- 0-3 years
- 3-10 years
- More than 10 years

12. Are you a current or former smoker of cigarettes and/or pipes?

(Select only one.)

- Yes
- No

13. If YES, what was or is the average number of cigarettes/pipes smoked per day?

(Select only one.)

- _____ cigarettes
- _____ pipes

14. If YES, what was the total number of years as a smoker?

_____ Years

17. What is your current height and weight?

_____ feet _____ inches _____ pounds

18. How many times have you visited your primary care provider due to breathing problems in the past 12 months?

_____ Times

19. How many times have you visited an emergency department due to breathing problems in the past 12 months?

_____ Times

Appendix F
Institutional Review Board Approval

Principal Investigator Notification:

From: Mayo Clinic IRB

To: Marnie Wetzstein

CC: Linda Chlan

Marnie Wetzstein

Re: IRB Application #: [17-007672](#)

Title: Examining Determinants of Patient Activation in Chronic Obstructive Pulmonary Disease: A Cross-Sectional Survey Study

IRBe Protocol Version: 0.02

IRBe Version Date: 10/4/2017 2:06 PM

IRB Approval Date: 10/24/2017

IRB Expiration Date: 10/23/2018

The above referenced application is approved by expedited review procedures (45 CFR 46.110, item 5,7). This approval is valid for a period of one year. The Reviewer conducted a risk-benefit analysis, and determined the study constitutes minimal risk research. The Reviewer determined that this research satisfies the requirements of 45 CFR 46.111.

The Reviewer approved the accrual of 120 subjects.

The Reviewer accepts the appointment of the Mayo Clinic IRB as the IRB of Record for the Relying Organization, University of North Dakota, and notes receipt of the fully executed IRB Authorization Agreement.

The Reviewer noted that oral consent with HIPAA authorization is appropriate for this study. The oral consent script was reviewed and approved as written. The written HIPAA form was reviewed and approved as written. The Reviewer approved waiver of the requirement for the Investigator to obtain a signed consent form in accordance with 45 CFR 46.117 as justified by the Investigator.

AS THE PRINCIPAL INVESTIGATOR OF THIS PROJECT, YOU ARE RESPONSIBLE FOR THE FOLLOWING RELATING TO THIS STUDY.

- 1) When applicable, use only IRB approved materials which are located under the documents tab of the IRBe workspace. Materials include consent forms, HIPAA, questionnaires, contact letters, advertisements, etc.
- 2) Submission to the IRB of any modifications to approved research along with any supporting documents for review and approval prior to initiation of the changes.
- 3) Submission to the IRB of all Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSO) and major protocol violations/deviations within 5 working days of becoming aware of the occurrence.
- 4) Compliance with applicable regulations for the protection of human subjects and with Mayo Clinic Institutional Policies.

Appendix G
Institutional Review Board Authorization Agreement



INSTITUTIONAL REVIEW BOARD (IRB)
OFFICE FOR HUMAN RESEARCH PROTECTION

Authorization Agreement

Institution Name (Relying Organization): University of North Dakota
OHRP Federalwide Assurance Number: FWA00000376

Mayo Clinic (Reviewing IRB)
OHRP Federalwide Assurance Number: FWA00005001
IRB Organization Number: IORG0000016
IRB Registration Numbers: IRB00000020; IRB00003294; IRB00003295; and IRB00005256
(collectively, the "Mayo IRB")

The Officials signing below agree that University of North Dakota may rely on Mayo Clinic IRB reviews and continuing oversight of its human subjects research described below:

This agreement is limited to the following specific protocol:

Name of Research Project: Examining Determinants of Patient Activation in Chronic
Obstructive Pulmonary Disease: A Cross-Sectional Survey Study

Mayo IRB #: 17-007672
Name of Mayo Principal Investigator: Marnie Wetzstein, RN

Relying Organization IRB #: IRB-201705-334
Name of Relying Organization Investigator: Marnie Wetzstein, RN

The review performed by the Mayo Clinic IRB will meet the requirements of the Relying Organization's OHRP-approved FWA. The Mayo Clinic IRB will follow written procedures for reporting its findings to appropriate officials at the Relying Organization. As described in Exhibit A, relevant minutes of Mayo Clinic IRB meetings shall be made readily available to the Relying Organization, and the Relying Organization remains responsible for ensuring compliance with the Mayo Clinic IRB's determinations and with the terms of its OHRP-approved Federalwide Assurance. This document should be kept on file at both institutions and must be provided to OHRP upon request.

This Agreement shall become effective upon the last date signed below and shall continue for the duration of the protocol. The Agreement will automatically terminate upon completion of the protocol. Either party may terminate this Agreement without cause upon 60 days prior written notice, or upon 14 days prior written notice in the event of a breach by the other party that is not cured to the reasonable satisfaction of the non-breaching party within said 14-day notice period. Participation in this Agreement will terminate immediately in the event of and as of the effective date of any suspension, restriction, termination, or expiration of either party's FWA.

In the event of any expiration or termination of this Agreement, the Relying Organization will remove the Mayo Clinic IRBs from the list of designated IRBs on its FWA (if it had included the Mayo Clinic IRBs on this list).

Signatory Official for Relying Organization: Barry Milavetz, Ph.D.
(printed name)

Title: Associate Vice President for Research & Economic Development

Signature:  Date: 10/9/17

Signatory Official for Mayo Clinic:  Date: 10/9/2017

Laura Samuell
IRB Administrator



Authorization Agreement

EXHIBIT A

The following division of responsibilities is based on the premise that the Mayo Clinic IRB's primary function is *initial and continuing review of protocols* and that the Relying Organization's primary function is *consideration of local context and oversight of local performance* for these protocols. The Relying Organization, either through its Signatory Official or its own local IRB, will decide on a protocol-by-protocol basis whether to accept the review of the Mayo Clinic IRB or to conduct its own review of the protocol.

The responsibilities of the Mayo Clinic IRB are to:

- 1) Serve as the Privacy Board to fulfill the requirements of the HIPAA Privacy Rule for use or disclosure of protected health information for research purposes.
- 2) Perform initial reviews of new protocols, discuss any issues with the Study Chair, and make a final decision of approval or disapproval of the protocol;
- 3) Notify the Relying Organization of those Mayo Clinic IRB-approved protocols for which the Relying Organization IRB may rely on the Mayo Clinic IRB review.
- 4) Maintain and make accessible to a designated contact or local IRB at the Relying Organization the Mayo Clinic IRB application, protocol reviews, letters to Study Chairs, approvals and disapprovals, and minutes of the Mayo Clinic IRB meetings;
- 5) Carry out Continuing Reviews, reviews of Unanticipated Problems Involving Risks to Subjects or Others, reviews of protocol amendments, reviews of DSMB reports, and reviews of any other documents submitted by the lead organization or Study Chair;
- 6) Notify each Relying Organization that has accepted the Mayo Clinic IRB review of any new materials that have been reviewed for an active protocol and any changes in the protocol approval status;
- 7) Maintain an OHRP approved Federalwide Assurance for human subjects research;
- 8) Maintain a Board membership that satisfies the requirements of 45 CFR 46 and provide special expertise as needed from Board members or consultants to adequately assess all aspects of each protocol;
- 9) Make available to the Relying Organization the roster of Mayo Clinic IRB membership and the IRB Policy Manual and Standard Operating Procedures;
- 10) Ensure that Mayo Clinic IRB members receive initial and continuing education on topics relevant to human subjects protections;
- 11) Notify the Relying Organization immediately if there is ever a suspension or restriction of the Mayo Clinic IRB's authorization to review protocols; and
- 12) Notify the Relying Organization of any Mayo Clinic IRB policy decisions or regulatory matters that might affect the organization's reliance on Mayo Clinic IRB reviews or performance of the research at the Relying Organization.



Authorization Agreement

The responsibilities of the Relying Organization are to:

- 1) Ensure the safe and appropriate performance of the research at its institution. This includes, but is not limited to, monitoring protocol compliance, any major protocol violations, and any serious adverse events occurring at the institution, and providing a mechanism by which complaints about the research can be made by local study participants or others. Any actions taken as a result of problems that are identified in these areas should be shared with the Mayo Clinic IRB and reported as required by the procedures established by the protocol's lead organization;
- 2) Ensure that the investigators and other staff at the local institution who are conducting the protocol are appropriately qualified and meet the institution's standards for eligibility to conduct research;
- 3) Notify the Mayo Clinic IRB immediately if there is a suspension or restriction of a local investigator;
- 4) Provide to the Mayo Clinic IRB and keep current the names and addresses of local contact persons who have authority to communicate for the Relying Organization, such as the local IRB administrator;
- 5) Establish a procedure by which the Relying Organization will receive and review the Mayo IRB materials for protocols to be performed at the local institution. For each Mayo IRB reviewed protocol (approval or disapproval) that is submitted by a local investigator:
 - Review the Mayo Clinic IRB's materials;
 - Determine if there are any local context issues that must be addressed by the Relying Organization;
 - Determine if the Mayo Clinic IRB review is acceptable to the Relying Organization; and
 - Decide whether to accept the Mayo Clinic IRB review or conduct a separate local IRB review;
 - Report to the Mayo Clinic IRB the decision about local acceptance/rejection of the Mayo Clinic IRB review; and
 - Notify the Mayo Clinic IRB if there is ever a change in the acceptance/rejection of the Mayo IRB review.
- 6) As appropriate, add local restrictions, stipulations, or substitutions to Mayo Clinic IRB approved informed consents. Deletion of Mayo Clinic IRB approved requirements in the protocol and Informed Consent Form is not allowed, and substantive changes that affect the meaning of Mayo Clinic IRB approved requirements are not allowed;
- 7) If the Relying Organization accepts the Mayo Clinic IRB approval of a protocol, maintain in their records documentation of the decision and evidence that it has received and considered all Mayo Clinic IRB material relevant to the protocol;
- 8) Maintain an OHRP approved Federalwide Assurance for human subjects research;
- 9) Maintain a human subjects protection program, as required by the DHHS OHRP;
- 10) Ensure that local investigators receive initial and continuing education on the requirements related to human subjects protections;
- 11) Notify the Mayo Clinic IRB immediately if there is ever a suspension or restriction of the local IRB's authorization to review protocols; and
- 12) Maintain compliance with any additional state, local, or institutional requirements related to the protection of human subjects.

Appendix H IRB-Approved Contact Letter

IRB 10140.005

Mayo Clinic: Office for Human Research Protection Contact Letter Template

(Date)

{ Name }
{ Street Address }
{ City, State Zip }

RE: *{ first name } { last name }*
MC#: *{ mc # }*

Protocol Title: Examining Determinants of Patient Activation in Chronic Obstructive Pulmonary Disease: A Cross-Sectional Survey Study

Mayo Clinic IRB #17-007672 and University of North Dakota IRB#201706334
Principal Investigator: Marnie M. Wetzstein, BSN, PhD(c), RN
Mayo Clinic Co-Investigator: Linda Chlan, PhD, RN
University of North Dakota Advisor: Linda Shanta, PhD, RN

Dear *{ Mr., Ms, or Mrs. }*

You are being asked to participate in a research study examining the relationships between characteristics of people living with chronic obstructive pulmonary disease (COPD), their experiences with the condition, and a new health concept called patient activation. Patient activation plays an important role in how well people are able to self-manage chronic disease. However, little is known about patient activation development in people living with COPD. The findings from this study will provide new information that may help nurses provide better self-management support to people with COPD. You are being contacted to participate in this study because you have a medical diagnosis of COPD, chronic bronchitis, or emphysema, and have completed pulmonary function testing at the Mayo Clinic.

If you agree to participate in this study you will be asked to complete a questionnaire. The questionnaire contains questions about you, your health experiences with COPD, and feelings about self-management. It may take you about 20-25 minutes to complete the questionnaire. After you return the questionnaire, we will access your medical record to obtain your most recent pulmonary function test results; these will be used to describe the severity of your lung condition. Any personal health information that you provide or is collected from your medical record during participation in this study will be treated as confidential. We have enclosed a questionnaire for you to complete. If you would like to, you may fill it out and return in the enclosed stamped envelope.

The risks of this research study are minimal, which means that we do not believe that they will be any different than what you would experience at a routine clinical visit or during your daily life. You may refuse to answer any question(s) that you do not wish to answer.

You will not benefit directly from taking part in this research study. It is for the benefit of research. However, others with COPD may potentially benefit in the future from what we learn in this research study. You will not receive compensation for your participation in this study.

IRB# 17-007672

Please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty. Specifically, your current or future medical care at Mayo Clinic will not be jeopardized if you choose not to participate.

If you decide to participate, you will need to read and sign the Authorization to Use and Disclose Protected Health Information (HIPAA) form and return it with the questionnaire. We are not allowed to use your answers without your signature on the HIPAA form. An extra copy is included for your records.

Contact me or my co-investigators if you have any questions about:

- Study procedures
- Withdrawing from the research study
- Materials you receive

Marnie M. Wetzstein, RN
Eisenberg 4A
200 West Center Street
Rochester, MN 55903
(507) 266-4813

Linda Chlan, PhD, RN
Nursing Research
Rosa Parks Pavilion
Rochester, MN 55903
(507) 284-7859

Linda Shanta, PhD, RN
UND College of Nursing
430 Oxford Street, Stop 9025
Grand Forks, ND 58202-9025
(701) 226-0673

Contact the Mayo Institutional Review Board (IRB) to speak to someone independent of the research team at 507-266-4000 or toll free at 866-273-4681 or the University of North Dakota IRB at 701-777-4279 you have questions about:

- Rights of a research participant
- Use of your Protected Health Information
- Stopping your authorization to use your Protected Health Information

Research-related questions not listed above, or any research-related complaints may also be addressed to me. If you prefer to speak with someone independent of the research team, you may contact the Mayo Clinic or University of North Dakota Institutional Review Boards (IRB).

If you prefer to complete the survey over the phone, or if you do not wish to participate, please indicate on the next page and return this letter since it will make a follow-up postcard unnecessary. Thank you very much for your time and consideration.

Sincerely,

[Name]

RE: *{first name} {last name}*
MC#: *{mc #}*

Protocol Title: Examining Determinants of Patient Activation in Chronic Obstructive Pulmonary Disease: A Cross-Sectional Survey Study
Mayo Clinic IRB #17-007672 and University of North Dakota IRB#201706334
Principal Investigator: Marnie M. Wetzstein, BSN, PhD(c), RN

I would prefer to complete the survey over the phone. I am **enclosing the Authorization to Use and Disclose Protected Health Information form** only. Please call me.

Your name: _____
Telephone number: () ____ - ____
Today's date: __/__/__
Best time to call: Morning Afternoon Evening
Best day(s) to call: _____

I am **not** willing to participate in this research study.

Appendix I IRB-Approved Reminder Postcard



Examining Determinants of Patient Activation in Chronic Obstructive Pulmonary Disease:
A Cross-Sectional Survey Study
Mayo Clinic IRB: #17-007672, University of North Dakota IRB: #201705-334
Principal Investigator: Marnie M. Wetzstein, BSN, PhD(c), RN
Phone: 507-266-4813

Dear (),

Three weeks ago, you received an invitation participate in a research study examining factors which influence how people with COPD self-manage their lung condition. If you have already returned the study questionnaire, we thank you!

If you are interested in participating in this study, we would appreciate your time and attention to complete the provided questionnaire. Please return it in the provided postage-paid envelope with your signed HIPAA authorization. The questionnaire should take no more than 20-25 minutes to complete. If you are not interested in participating in this study at this time, you may return the decline letter enclosed in the study mailing. If you have any questions about this study, please contact me at the number or email address below.

Sincerely,

Marnie M. Wetzstein, RN

Nurse Study Coordinator, Mayo Clinic
Doctoral Candidate, University of North Dakota



Appendix J
Health Insurance Accountability and Portability Act (HIPAA) Authorization



*HIPAA Authorization to Use and Disclose
Protected Health Information*

Name and Clinic Number

Approval Date: October 24, 2017
Not to be used after: October 23, 2018

Your Privacy Rights

You do not have to sign this form, but if you do not, you cannot take part in this research study. Your decision won't change the access to medical care or any other benefits you get at Mayo Clinic now or in the future.

If you cancel your permission to use or share your health information, your participation in this study will end and no more information about you will be collected; however, information already collected about you in the study may continue to be used.

You can cancel your permission to use or share your health information at any time by sending a letter to the address below:

Mayo Clinic
Office for Human Research Protection
ATTN: Notice of Revocation of Authorization
200 1st Street SW
Rochester, MN 55905

Alternatively, you may cancel your permission by emailing the Mayo Clinic Research Subject Advocate at: researchsubjectadvocate@mayo.edu.

Please be sure to include in your letter or email:

- The name of the Principal Investigator,
- The study IRB number and /or study name, and
- Your contact information.

Your permission lasts until the end of this study, unless you cancel it. Because research is an ongoing process, we cannot give you an exact date when the study will end.

Your signature documents your permission to use your protected health information for this research.

_____/_____/_____:____ AM/PM
Printed Name Date Time

Signature

Appendix K
Institutional Review Board Approval (Pilot Study)



DIVISION OF RESEARCH & ECONOMIC DEVELOPMENT

UND.edu

Institutional Review Board

Twamley Hall, Room 106
264 Centennial Dr Stop 7134
Grand Forks, ND 58202-7134
Phone: 701.777.4279
Fax: 701.777.6708
Email: UND.irb@research.UND.edu

May 9, 2017

Principal Investigators:	Marnie Wetzstein
Project Title:	Examining Determinants of Patient Activation in Chronic Obstructive Pulmonary Disease: A Cross-Sectional Survey Study
IRB Project Number:	IRB-201705-334
Project Review Level:	Exempt 2
Date of IRB Approval:	05/08/2017
Expiration Date of This Approval:	05/07/2020

The application form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

Attached is your original informed consent statement that has been stamped with the UND IRB approval and expiration dates. Please maintain this original on file. You must use this original, stamped consent form to make copies for participants. No other consent form should be used, and no signatures should be obtained from participants. Each participant must be given a copy of the informed consent statement to keep for their records.

The Principal Investigator must provide a copy of the approvals from COPD PPRN Research Review Committee and ALA Better Breathers Club to the UND IRB Office prior to beginning any research with participants from these organizations.

If you need to make changes to your research, you must submit a Protocol Change Request Form to the IRB for approval. No changes to approved research may take place without prior IRB approval.

This project has been approved for 3 years, as permitted by UND IRB policies for exempt research. You have approval for this project through the above-listed expiration date. When this research is completed, please submit a Termination Form to the IRB.

The forms to assist you in filing your project termination, adverse event/unanticipated problem, protocol change, etc. may be accessed on the IRB website: <http://und.edu/research/resources/human-subjects/>

Sincerely,

Michelle L. Bowles, M.P.A., CIP
IRB Coordinator

MLB/sb

Enclosure

Cc: Linda Shanta, Ph.D., RN (w/o attachment)

The University of North Dakota is an equal opportunity / affirmative action institution.

**UNIVERSITY OF NORTH DAKOTA
Institutional Review Board
Informed Consent Statement**

Title of Project: Examining determinants of patient activation in chronic obstructive pulmonary disease: A cross-sectional survey study

Principal Investigator: Marnie M. Wetzstein, BSN, RN, (507) 252-1487, marnie.wetzstein@und.edu

Advisor: Linda Shanta, PhD, RN, (701) 226-0673, linda.shanta@und.edu

Purpose of the Study:

The purpose of the study is to examine relationships among the characteristics of people living with COPD, the health outcomes they experience, and a health concept called patient activation. Patient activation plays a significant role in how well people self-manage chronic diseases, like COPD. Little is known about how patient activation develops in people living with COPD. The findings from this study will provide new information that may help nurses provide more effective self-management training and support to patients with COPD, and thus, improve their health.

You are being contacted to participate in this study because you are participating in the patient registry of the COPD Patient-Powered Research Network.

Procedures to be followed:

Your participation will involve answering a web-based or paper study questionnaire, based on your preference. The questions were chosen to help us learn about your feelings and health experiences living with COPD and measure your patient activation level. You will also be asked basic demographic questions, to help us describe and understand the characteristics of people who participate in this study.

Risks:

There are no risks in participating in this research beyond those experienced in your everyday life.

Benefits:

You may not receive a direct benefit if you agree to participate. However, people in the future may benefit from the information obtained from this research.

Duration:

It will take about 20-25 minutes to complete the questionnaire.

Statement of Confidentiality:

The questionnaire does not ask for any information that would identify who the responses belong to. Therefore, your responses are recorded anonymously. If this research is published, no information that would identify you will be included, since your name is in no way linked to your responses.

All survey responses that we receive will be treated confidentially and stored on a secure computer server. However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant

Approval Date: <u> MAY - 8 2017 </u>
Expiration Date: <u> MAY - 7 2020 </u>
University of North Dakota IRB

in our study, we want you to be aware that certain "key logging" software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

Right to Ask Questions:

The researchers conducting this study are Marnie Wetzstein, BSN, RN and Linda Shanta, PhD, RN. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Marnie Wetzstein by telephone at (507) 252-1487 or by email at marnie.wetzstein@und.edu or Dr. Linda Shanta at (701) 226-0673, linda.shanta@und.edu.

If you have questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at (701) 777-4279. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

General information about being a research subject can be found on the Institutional Review Board website "Information for Research Participants" <http://und.edu/research/resources/human-subjects/research-participants.cfm>

Compensation:

You will not receive compensation for your participation.

Voluntary Participation:

You do not have to participate in this research. You can stop your participation at any time. You may refuse to participate or choose to discontinue participation at any time without losing any benefits to which you are otherwise entitled.

- You do not have to answer any questions you do not want to answer.
- You must be 18 years of age older to consent to participate in this research study.
- Completion and return of the questionnaire implies that you have read the information in this form and consent to participate in the research.
- Please keep this form for your records or future reference.

Approval Date: <u> MAY - 8 2017 </u>
Expiration Date: <u> MAY - 7 2020 </u>
University of North Dakota IRB

Appendix L
American Lung Association Minnesota Better Breathers Club Approval



Board of Directors

Chair
James Ehlen, MD

Chair Elect
Craig Schilling, PharmD

Directors
Carin Anderson
Ken Bence
Gail Brottman, MD
Angie Carlson, PhD
Steven Christopher
Catherine Erickson, RN
Vicki Klasell
Susan Kratz
Heidi Larson
Audrene Lojovich
David Midthun, MD
Lin Nelson
Sara Ratner
Arnel Rillo
Richard Sveum, MD
Dave Tjaden
Richard Woellner, MD

Executive Director
Jessica Ryan

July 11, 2017

Institutional Review Board
University of North Dakota
Twamley Hall, Room 106
264 Centennial Dr. Stop 7134
Grand Forks, ND 58202-7134

Dear Institutional Review Board:

I have been approached by Marnie Wetzstein, PhD(c), RN regarding accessing the Better Breathers Clubs of St. Paul and Minneapolis, of which I facilitate, to conduct a pilot study of her dissertation research titled, *Examining determinants of patient activation in chronic obstructive pulmonary disease: A cross-sectional survey study* (IRB-201705-334). Ms. Wetzstein has explained the purpose of her research and the need to engage with a sample of people living with COPD in the community to assess (a) the readability of the study questionnaire used for data collection and (b) the time needed to complete the tool, prior to implementing her larger study.

I am willing to help Ms. Wetzstein with this request. She will be invited to attend an upcoming Better Breathers meeting to talk with group members about her research and may provide interested attendees the study survey.

Sincerely,

Cheryl Sasse, RRT
American Lung Association

424 W Superior St, Ste 202 | Duluth, MN 55802
Ph: 218-726-4721 F: 218-726-4722

490 Concordia Ave | St. Paul, MN 55103
Ph: 651-227-8014 F: 651-227-5459 Info@LungMN.org

Please remember the American Lung Association in your will or trust.

1-800-LUNGUSA | Lung.org

Appendix M
Permission to use the Patient Activation Measure-13

From: Teresa Belfanti <tbelfanti@insigniahealth.com>
Sent: Friday, May 5, 2017 11:46 AM
To: Wetzstein, Marnie
Subject: RE: Insignia Health Yahoo Store - Order 1715

Marnie,

Thank you for the additional information. Your request has been approved.

Pursuant to the terms of your order, I have attached the documents you will need to use PAM:

- PAM survey and coaching guidance (PAM 13 License Package)
- Excel sheet for entering and tracking PAM survey responses.

Once your data is captured on the Excel sheet you can submit it to me at tbelfanti@insigniahealth.com. I will have the surveys scored and return the results to you.

In addition to submitting the Excel sheet, the research license requires that you share your entire de-identified data set with Insignia Health when you send your survey capture spreadsheet.

With regards to your questions below, there have been changes made to how the research licenses are approved and administered. Insignia Health will now score the surveys for better accuracy. Providing your de-identified PAM data allows for enhanced feedback regarding your research.

Please feel free to contact me if you have any questions. We look forward to working with you on this effort.

Sincerely,

Teresa Belfanti
Insignia Health, LLC
952.582.4374
tbelfanti@insigniahealth.com

Appendix N
Permission to use Revised Wilson Cleary Model

RE: Permission to use conceptual model

FJ Ferrans, Carol J <cferrans@uic.edu>
Mon 2/8/2016, 11:18 AM
Wetzstein, Marnie

Reply all |

Reply all | Delete Junk |

Flag for follow up. Completed on Tuesday, March 01, 2016.

You forwarded this message on 2/21/2016 1:21 PM

Dear Ms. Wetzstein,

Thank you for your email. I am pleased to grant you permission to use our model for your dissertation study, as described in your email below.

I wish you every success with your work.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Professor and Associate Dean for Research
University of Illinois at Chicago
College of Nursing (M/C 802)
[845 S. Damen Avenue \(Room 606\)](#)
[Chicago, IL 60612](#)
Phone 312.996.8445
Fax 312.996.4979

From: Wetzstein, Marnie [mailto:marnie.wetzstein@und.edu]
Sent: Saturday, February 06, 2016 3:27 PM
To: Ferrans, Carol J <cferrans@uic.edu>
Subject: Permission to use conceptual model

Dear Dr. Ferrans,

I am writing to request permission to utilize the Revised Wilson and Cleary Model for health-related quality of life, as explicated in your publication with Drs. Zerwic, Wilbur, and Larson in 2005. (Ferrans, C., Zerwic, J., Wilbur, J. & Larson, J. (2005). Conceptual model of health-related quality of life. *Journal of Nursing Scholarship*, 37(4), 336-342.)

I am interested in using the revised version of the Wilson Cleary model for health-related quality of life as a conceptual frame for my dissertation work examining relationships among health outcome factors and health activation and quality of life in chronic obstructive pulmonary disease. The revised model best supports my research questions that will investigate the role of gender (individual characteristic) and health care access (environmental characteristic) as potential mediators of biological function and thus, level of activation for self-management in this population.

Sincerely,

Marnie Wetzstein, RN

Appendix O
Permission to use Pulmonary Function -Modified

Re: Request for use of tool

LS Lareau, Suzanne <Suzanne.Lareau@ucdenver.edu>   Reply all | 
Fri 8/26/2016, 4:42 PM
Wetzstein, Marnie 

Inbox

You replied on 8/27/2016 9:35 AM.

 Action Items 

Happy to provide permission.
If you need copies of instrument and workbook let me know.
I can send on Monday
Sue Lareau

Sent from my iPad

On Aug 26, 2016, at 9:18 AM, Wetzstein, Marnie <marnie.wetzstein@und.edu> wrote:

Dear Ms. Lareau,
I am writing today to request permission to use and access to the Pulmonary Functional Status and Dyspnea Questionnaire-Modified version for use in my dissertation research. I am planning to examine multiple health outcome domains in COPD as determinants of patient activation level—functional status being one of these.
I greatly appreciate your consideration of this request!
Sincerely,
Marnie M. Wetzstein, RN, PhD(c)

University of North Dakota
College of Nursing and Professional Disciplines

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